

# **New Jersey Comprehensive Cancer Control: Status Report to the Governor**

*From the Task Force on  
Cancer Prevention, Early Detection and  
Treatment in New Jersey*

**December 2004**

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**Prepared under the auspices of the Task Force  
Evaluation Committee**

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### Abridged Version

This version is 90 pages. The unabridged version, 690 pages, is available upon request from the OCCP, NJDHSS.

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<sup>a</sup> These were included in the unabridged report, and are available upon request from the OCCP.

## Executive Summary

### **Comprehensive Cancer Control...what is it and why evaluate?**

The purpose of comprehensive cancer control is to develop “an integrated and coordinated approach to reduce the incidence, morbidity, and mortality of cancer through prevention, early detection, treatment, rehabilitation, and palliation.”<sup>a</sup>

“The availability of adequate evaluative information is crucial, not only for effective implementation of the [Comprehensive Cancer Control] Plan, but also for development of future plans.”<sup>b</sup>

### **Background and Purpose of the Report**

New Jersey Executive Order 114 established the Task Force on Cancer Prevention, Early Detection and Treatment in New Jersey (Task Force) on May 9, 2000. The Task Force developed a comprehensive cancer control plan (NJ-CCCP), released by the Governor in January 2003, which focused on seven priority cancers (breast, cervical, colorectal, lung, melanoma, oral/oropharyngeal, and prostate) and dealt with overarching issues (such as cancer disparities) and matters related to the future of cancer control and prevention in New Jersey. The Executive Order mandated biennial updated reports. The NJ-CCCP Evaluation Chapter states that evaluation shall be conducted by a New Jersey academic institution, in partnership with the Task Force. This led to the establishment of an Evaluation Committee. The Task Force delegated to the Evaluation Committee the preparation of the biennial report on its behalf. This report is the first biennial update, summarizing the impressive progress over the last two years with respect to the NJ-CCCP, with detailed information contained in the appendices.

The Executive Order mandated, in part, attention to reduction in cancer mortality, in behaviors that increase the risk of cancer, and in cancer disparities. Assessment of extant evaluation efforts by other states, including discussions with high-level programmatic officials at the Centers for Disease Control and Prevention, National Cancer Institute, and American Cancer Society, revealed that the current state of the art focused solely on qualitative and limited quantitative measures of process, rather than these health measures. Thus, the Task Force, in the NJ-CCCP, decided that establishing an academically based Evaluation Committee and conducting a comprehensive cancer needs assessment were both early necessities. The diversity of New Jersey, as reflected in heterogeneous counties with varying mixtures of urban, suburban, and rural communities and with wide ranges of socioeconomic indicators and cultural backgrounds, pointed to a need to examine each county individually with direct involvement from local experts.

<sup>a</sup> Centers for Disease Control and Prevention, [www.cdc.gov/cancer/ncccp/index.htm](http://www.cdc.gov/cancer/ncccp/index.htm)

<sup>b</sup> Page *viii* of the New Jersey Comprehensive Cancer Control Plan.

The Evaluation Committee thus determined that implementation and evaluation of the NJ-CCCP required:

- The creation of a baseline capacity and needs assessment, including involvement of local health planners and the communities, for each county, an approach not previously undertaken in New Jersey or in any other state;
- The development of a standardized database of health care resources;
- The creation of mechanisms to systematically collect data to monitor the extent of progress and achievement;
- The utilization of standardized methods and time periods for cancer data in order to establish common baselines and enable valid comparisons.<sup>c</sup>

The present report details the development and establishment of structures to accomplish these tasks. In addition, it summarizes progress to date and delineates the baseline status of salient indices concerning cancer in order to facilitate ongoing monitoring and evaluation. It remains too early to assess progress towards meeting the goals and challenges for the year 2010 that are presented in the Executive Order. The actions and policies initiated by the Task Force and its collaborators that are outlined in this report are nevertheless anticipated to be major factors in achieving these goals.

### **Current Status of Cancer in New Jersey**

The annual incidence rate of cancer in New Jersey in 2001 (520.4 per 100,000) was the second highest in the nation – 12% higher than the corresponding U.S. rate in 2000 (464.2 per 100,000).<sup>d</sup> In 2001, the annual cancer mortality rate in New Jersey (203.0 per 100,000) was the 18<sup>th</sup> highest state in the nation – similar to the national rate (195.6 per 100,000). The mortality rate among New Jersey blacks (242.0 per 100,000) was 20% higher than the rate among New Jersey whites (202.5), a pattern also seen nationwide. Although New Jersey has consistently had higher cancer mortality rates than the U.S. for over 25 years, this gap is steadily narrowing. The gap in incidence has persisted over time. Furthermore, the incidence rates both in men and in women have risen from 1979 to 2001. With the introduction of screening programs, an increase in detection of cancer is expected, with the hope of a shift toward an earlier stage of diagnosis. A compensatory decrease in detection may follow in subsequent years. Since most cancers in New Jersey remain diagnosed at non-localized stages, and since the gap in incidence has persisted, the high incidence rate in New Jersey does not appear to be attributable to the impact of screening. It does, in part, reflect the disproportionately high incidence of many cancers in blacks, highlighting the importance of attention to correcting disparities.

In summary, there has been an improvement in cancer mortality but a rise in cancer incidence. This discrepancy suggests a need to emphasize funding for comprehensive cancer control efforts, including tobacco control. Given the high incidence of cancer and its impact on the residents of New Jersey, cancer should remain a high statewide priority and the State Government should increase state funding to combat cancer.

<sup>c</sup> For example, updating the reference population that is used for age-standardization, such as in targets of *Healthy New Jersey 2010* that are used in the NJ-CCCP. Currently reported cancer incidence and mortality rates should not be compared with previously published targets until the latter have been adjusted to account for the intervening changes in how these statistics are computed.

<sup>d</sup> Incidence and mortality rates in this report have been standardized to the 2000 U.S. Census population standards.

## Summary of Recent Initiatives

The Cancer Resource Database of New Jersey (CRDNJ) was developed in support of the C/NAs, and provides the first comprehensive delineation of resources in New Jersey; it has already been acknowledged by leading national organizations as a new model for other states. The CRDNJ is expected to be useful in assisting county and local health departments, such as in their preparation of required Community Health Improvement Plans, and in informing the public, health planners, and researchers about resources available locally. Data from the CRDNJ used in conjunction with the C/NA results have helped identify disparities that need to be addressed. The CRDNJ is further evolving to incorporate geographic information systems technology.

- Advocacy and opportunities for collaboration
- Coalitions
- Data needs and data sharing
- Analysis of existing data, including identification of disparities and gaps in resources
- Emerging cancer trends and items for further review and evaluation

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## Section 1 – Task Force and Roles of Collaborators

### **Task Force on Cancer Prevention, Early Detection and Treatment in New Jersey**

The Task Force on Cancer Prevention, Early Detection and Treatment in New Jersey (Task Force)<sup>a</sup> was created by New Jersey Executive Order 114<sup>b</sup>, issued on May 9, 2000. The Executive Order was issued by former Governor Christine Todd Whitman, and each succeeding Governor has endorsed the mission of the Task Force. In conjunction with the Task Force, the Office of Cancer Control and Prevention (OCCP)<sup>c</sup> was formed as a program within the Office of the State Epidemiologist in the New Jersey Department of Health and Senior Services (NJDHSS). The OCCP is dedicated to coordinating cancer control efforts in New Jersey and participates in the national efforts of the U.S. Centers for Disease Control and Prevention (CDC) to establish state-based comprehensive cancer control plans. A chronology of key milestones and accomplishments of the OCCP may be found in Appendix C.

The Task Force<sup>d</sup> is composed of members appointed by the Governor. It addresses the impact of cancer on New Jersey residents by formulating and implementing a comprehensive cancer control plan for New Jersey. More specifically, the Task Force is charged to evaluate current trends in cancer incidence, morbidity, mortality, screening and diagnosis, in behaviors that increase the risk of cancer, and in historic, current and emerging cancer control strategies.<sup>e</sup> The Task Force adopted the CDC's operational definition of comprehensive cancer control as an “integrated and coordinated approach to reducing cancer incidence, morbidity, and mortality through prevention, early detection, treatment, rehabilitation and palliation.”<sup>a</sup>

### **New Jersey Comprehensive Cancer Control Plan**

On July 1, 2002, the State Government appropriated \$3.25 million in the NJDHSS budget for comprehensive cancer control. The first five-year Comprehensive Cancer Control Plan (NJ-CCCP) was released by then Governor James E. McGreevey on January 9, 2003.<sup>f</sup>

### ***Workgroups and Standing Committees***

During development of the NJ-CCCP, the Task Force established eight Workgroups. One Workgroup focused on each of the seven priority cancers of the NJ-CCCP (breast, cervical, colorectal, lung, melanoma, oral and oropharyngeal, and prostate); these Workgroups developed

<sup>a</sup> See Appendices A and B for details of the structure and membership of the Task Force.

<sup>b</sup> See <http://www.state.nj.us/infobank/circular/eow114.htm>

<sup>c</sup> The Executive Director of the OCCP is Margaret L. Knight, RN, MEd ([peg.knight@doh.state.nj.us](mailto:peg.knight@doh.state.nj.us)). See [www.state.nj.us/health/ccp/index.html](http://www.state.nj.us/health/ccp/index.html)

<sup>d</sup> See [www.state.nj.us/health/ccp/tf.htm](http://www.state.nj.us/health/ccp/tf.htm) When the Task Force was established, the Governor appointed sixteen members.

<sup>e</sup> In January 2003, the Commissioner of Health and Senior Services issued Executive Order 197 establishing a Task Force on Cancer Clusters in New Jersey with a charge including the evaluation of cancer cluster investigation policies, procedures, guidelines and best practices. Since they issued a comprehensive report dated April 2004, these issues are not further addressed in the present report.

<sup>f</sup> See [www.state.nj.us/cgi-bin/governor/njnewslines/view\\_article.pl?id=1000](http://www.state.nj.us/cgi-bin/governor/njnewslines/view_article.pl?id=1000)

Section II of the NJ-CCCP (Site-Specific Cancers, Chapters 6-12). The eighth Workgroup handled overarching issues (access and resources, advocacy, palliation, nutrition and physical activity, and childhood cancer) and developed Section I (Overarching Issues, Chapters 1-5). During initial implementation of the NJ-CCCP, the Task Force established three additional Workgroups (Childhood Cancer, Nutrition and Physical Activity, and Palliation) and three Standing Committees (Evaluation, Advocacy Ad Hoc, and Funding/Resources) to oversee key tasks not subsumed by these Workgroups. The issues related to access and resources (Chapter 1 of the NJ-CCCP), implementation (Chapter 14), and evaluation (Chapter 15) have become part of the purview of the Evaluation Committee. No Workgroup has been established surrounding issues in Chapter 13 (Emerging Trends), which covers Access to Clinical Trials, Cancer Survivorship, Complementary and Alternative Medicine, and Infection and Cancer. Strategies related to emerging trends are to be considered during the next planning cycle.

Each Workgroup developed an action plan, laying the groundwork for implementation of the NJ-CCCP. The action plans include goals and target dates for completion, with each Workgroup responsible for evaluating the progress of each strategy defined in its action plan. The OCCP and its partners – the 350 organizations and individuals who had assisted in development of the NJ-CCCP – set about implementing the NJ-CCCP. In so doing, they have become the “principal change agents” who together are assisting in addressing disparities in the cancer burden and in reducing the illness, death, and loss of productivity due to cancer in the State of New Jersey. An electronic database version of the NJ-CCCP has been created as a tool to support implementation of the NJ-CCCP and monitoring of progress.

Further details on the strategies and the electronic version of the NJ-CCCP are provided in Section 3.

The Workgroups and Standing Committees are composed of stakeholders in comprehensive cancer control: healthcare institutions, clinicians and other healthcare providers, cancer survivors and their families, community health groups, public health representatives, academicians, researchers, business leaders, government officials, and organization leaders. The interdisciplinary nature and broad base of participants in each Workgroup were instrumental in developing a consensus on key issues and strategies. At the release of the Plan, 350 people were involved in Workgroups; as of November 2004, there are over 550.<sup>g</sup>

### ***Subcommittee of the Colorectal Cancer Workgroup***

The Colorectal Cancer Workgroup recognized the importance of particular attention to screening issues and developed an internal subcommittee<sup>h</sup> to focus on colorectal cancer screening issues.

### **Collaborations of the NJ-CCCP**

Numerous entities are involved in the implementation and coordination of the NJ-CCCP. A summary of their roles follows.

<sup>g</sup> The full plan is available at [www.state.nj.us/health/ccp/ccc\\_plan.htm](http://www.state.nj.us/health/ccp/ccc_plan.htm).

<sup>h</sup> Chaired by Ms. Michelle Tropper (American Cancer Society).

Ultimate responsibility rests with the Office of the Governor, insofar as the impetus for the development of a comprehensive cancer control plan in New Jersey came from the gubernatorial Executive Order establishing the (appointed) Task Force on Cancer Prevention, Early Detection and Treatment in New Jersey. The Task Force provides overall guidance and sets overall policy, acting much like a board of trustees or directors of an organization in the non-governmental sector. The OCCP centrally coordinates the implementation of the NJ-CCCP under the general guidance of the Task Force. The OCCP is part of the NJDHSS Office of the State Epidemiologist, Center for Cancer Initiatives, under the direction of the Deputy Commissioner<sup>i</sup>.

Among the numerous community-based organizations that participate in the implementation of the NJ-CCCP, by far the largest role is played by the American Cancer Society, which collaborates extensively with the OCCP on comprehensive cancer control and has members on the Task Force and all of its Workgroups and Committees.

Other governmental or quasi-governmental bodies participating in the implementation of the NJ-CCCP include the New Jersey State Cancer Registry (NJSCR), which provides essential epidemiologic data, the Center for Health Statistics, which has provided invaluable data from the Behavioral Risk Factor Surveillance System (BRFSS), and the Cancer Institute of New Jersey's Comprehensive Cancer Center. The NJCEED program in the Division of Family Health Services of the NJDHSS administers in each county the CDC-funded breast and cervical screening programs. NJDHSS has extended the functions of these programs; the additional funding expands the number of clients beyond what the CDC funding covered and expands screening to include cancers beyond the scope of the federal program, viz. prostate and colorectal cancers.

The State Librarian and the librarians at the University of Medicine and Dentistry of New Jersey (UMDNJ) have been collaborating on a series of endeavors to expand access to reliable health information, particularly for the elderly and medically underserved populations. The web site [www.healthynj.org](http://www.healthynj.org), developed and maintained by the librarians, focuses on all health issues. It currently has limited information specific to cancer, but the existence of its administrative infrastructure provides a foundation to develop widespread dissemination of cancer-related information in the future. All parties recognize the crucial nature of education and of information dissemination as part of comprehensive cancer control efforts. In conjunction with the other web-based efforts led by UMDNJ on behalf of the OCCP, as described in this Report, as well as nationally-based web sites, expansion of the [www.healthynj.org](http://www.healthynj.org) site may be an efficient mechanism and nexus for promulgating cancer-related information to the public. Other relevant web sites newly developed for this project are based at the OCCP and UMDNJ web sites, and integral linkages between these two sites have already been developed.

### ***OCCP Joins the CDC National Comprehensive Cancer Control Program***

The organizational infrastructure of the OCCP has been enhanced through an award in 2004 (in the form of a cooperative agreement) from the Centers for Disease Control and Prevention (CDC) in response to Program Announcement 02060 for the National Comprehensive Cancer Control Program, which supports the planning and implementation of comprehensive cancer control activities at the state level. This award includes funding for two additional OCCP staff members. Their responsibilities include coordinating the newly funded, dedicated County

<sup>i</sup> Eddy Bresnitz, MD, MS is the Deputy Commissioner.



Coordinator positions in each of New Jersey's 21 counties, the internal monitoring of each of the Task Force Workgroups empowered to implement the Plan, as well as grant writing support for these Workgroups, and the dissemination of their best practices utilizing multimedia.

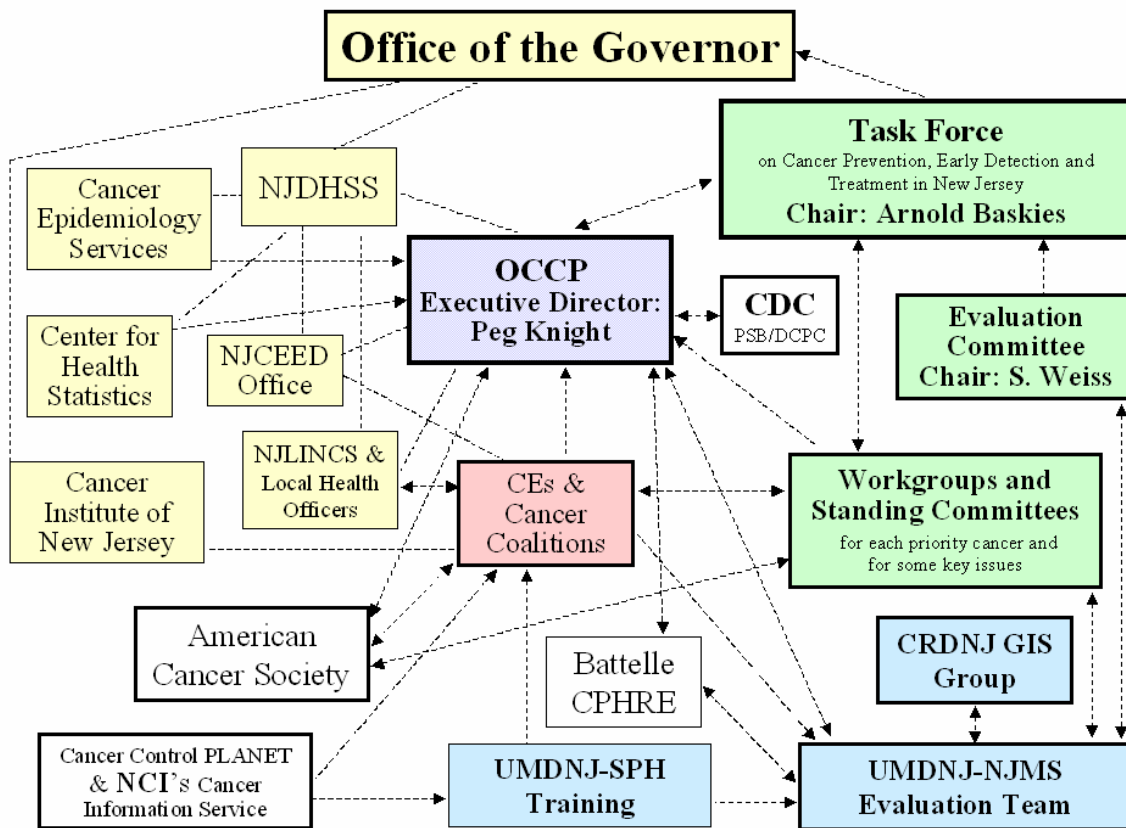
### Data Exchange Matrix for the NJ-CCCP

The diagram below illustrates some key interactions related to comprehensive cancer control in New Jersey. Additional information on some of the organizations within this matrix is described in later sections of this report.

### Collaboration and Data Exchange Matrix for the NJ-CCCP

**Dotted Line: Interaction/Collaboration between two entities**

**Arrow: Direction of Data Flow**



#### Abbreviations:

Battelle CHPRE: Battelle Centers for Public Health Research and Evaluation

Cancer Control PLANET: Plan, Link, Act, Network with, Evidence-based Tools

CDC: Centers for Disease Control and Prevention

CEs: County Evaluators

CRDNJ: Cancer Resource Database of New Jersey

GIS: Geographic Information System

NJCEED: New Jersey Cancer Education and Early Detection

NCI: National Cancer Institute

NJDHSS: New Jersey Department of Health and Senior Services

NJLINC: New Jersey Local Information Network and Communications System

OCCP: Office of Cancer Control and Prevention

PSB/DCPC: Program Services Branch, Division of Cancer Prevention

UMDNJ-NJMS: University of Medicine and Dentistry of New Jersey-New Jersey Medical School

UMDNJ-SPH: University of Medicine and Dentistry of New Jersey School of Public Health

The Task Force met quarterly during 2002, 2003, and 2004. Each Task Force member has been asked to either chair or be a member of a Workgroup or Standing Committee. The Evaluation Committee recommends that this involvement be fostered and extended, as it is an important structural feature that both provides essential perspectives to the Task Force through involvement in specific and concrete activities and enhances the Task Force's role in oversight.

The Task Force Chair<sup>j</sup> has been constant since the inception of the Task Force. This leadership has provided consistency and direction and instills collaboration and a high level of commitment from stakeholders throughout New Jersey. Furthermore, given the complexity of the NJ-CCCP, his experience, exemplary dedication, and in-depth knowledge are essential to its successful implementation. Continuity in leadership is required for continued success. The accomplishments described in further detail throughout this report attest to the effective leadership of the Chair and of the Task Force.

*Palliation Workgroup*

- Nutrition/Physical Activity and Colorectal Cancer Workgroups

- Target audiences have been identified
- Training sessions and other components of Body and Soul are under discussion
- Funding sources are being explored

- Statewide conference, “Childhood Cancer Survivors: Meeting Challenges,” scheduled for May 2005. Audience includes survivors and families, school, insurance, nursing, and social work communities, legislators, and general public. Conference objectives and

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● Survey of healthcare providers from the Medical Society Osteopathic Association and

- Consensus conference for development of a consistent message for breast cancer for

- Development of an education program to increase patient awareness under discussion

- Submitted grant proposal to conduct outreach in key urban areas (Jersey City, Newark)

• • • • •

*Melanoma Workgroup*

- 126 School districts participated in the “Train the trainer” initiative and further professional development in-service is being provided
- School nurse education program in discussion

*Oral and Oropharyngeal Cancer Workgroup*

- NIH grant proposal, incorporating ideas from various stakeholders, was developed and submitted<sup>k</sup> in December 2003
- The above proposal, which was modeled upon NJ-CCCP strategies, has helped to serve as a blueprint for statewide action
- New Jersey Dental Association to provide education on oral cancer screening
- Advocates for inclusion of oral cancer detection in the curriculum of the state’s medical and dental schools<sup>l</sup>
- Collaborates with the Oral Cancer Consortium ([www.oral-cancer.org](http://www.oral-cancer.org)), a multi-state initiative, whose endeavors include the organization of an annual screening day ([www.oral-cancer.org/screening.html](http://www.oral-cancer.org/screening.html))
- Advocated nationally for separate dental procedure codes for oral cancer screening, with an initial hearing on this issue scheduled for March 2005<sup>m</sup>
- Participates in anti-smoking initiatives, along with Lung Cancer Workgroup, the NJDHSS’s Comprehensive Tobacco Control Program ([www.state.nj.us/health/as/ctcp/](http://www.state.nj.us/health/as/ctcp/)), and other organizations (e.g. NJ Breathes, [www.kickbuttnj.com](http://www.kickbuttnj.com); NJ GASP, [www.njgasp.org](http://www.njgasp.org))

*Prostate Cancer Workgroup*

- Barbershop initiative, a nationwide project, is in planning stages in Newark. Exploring partners and funding sources.<sup>n</sup>
- Participation in the 2005 New Jersey Conference for Mayors currently in development, in collaboration with the American Cancer Society and OCCP

*Advocacy Ad Hoc Standing Committee*

- Successfully recruited new members
- Focused efforts on access to care and quality of life, supporting state and federal legislation:
  - Patient Navigator Bill
  - Childhood Pain Management
  - Clean indoor air (NJ Smoke Free Air Act)
  - Nutrition Bill
- Breast cancer advocacy guide developed through NJDHSS grant and widely distributed

<sup>k</sup> Dr. Weiss and staff prepared the proposal “New Jersey Model—Oral Cancer Prevention/Early Detection” on behalf of the Workgroup, in response to an NIH RFA-DE-04-005 for State Models for Oral Cancer Prevention and Early Detection - Phase II; it was approved but not funded.

<sup>l</sup> Dr. Arnold Rosenheck obtained the approval from the Deans of the New Jersey Medical School and the School of Osteopathic Medicine to include new modules in the curriculum, and from the Dean of the Robert Wood Johnson Medical School to expand the curriculum, concerning oral and oropharyngeal cancers.

<sup>m</sup> To be presented by Dr. Abraham Speiser.

<sup>n</sup> See <http://www.prostate-online.org/> and <http://www.prostate-online.org/barbershop/> organized by Mr. Virgil Simons (ProstateNet).

*Evaluation Standing Committee*

This committee and support staff (see Appendix A), in conjunction with the OCCP, have been providing overall guidance to the Task Force and the County Evaluators.<sup>o</sup>

- Provides scientific guidance to the Task Force
- Worked with the OCCP to develop a tracking database for the NJ-CCCP strategies, and maintain and review progress of these strategies
- Provided oversight to the county Capacity and Needs Assessment process and review of the Report Summaries

*Funding/Resources Standing Committee*

The Funding and Resources Standing Committee empowered each Workgroup to obtain funding for its activities. In conjunction with the Advocacy Ad Hoc Committee, the FY06 state budget for cancer control efforts is a major focus.

**Evaluation of the Task Force and its Activities**

The activities of the Task Force summarized above demonstrate consistent and productive implementation of the NJ-CCCP. Given the effectiveness of the current structure, the Workgroups should be retained. The Task Force should continue to assess periodically whether or not additional Workgroups are needed.

Synergies and partnerships across Workgroups have emerged, and projects that cover multiple chapters have been developed. For example, “Partnerships for Better Health in African Americans” is a joint project of the Colorectal Cancer Workgroup and the Nutrition and Physical Activity Workgroup. The Task Force should continue to encourage partnerships across Workgroups to maximize synergies, particularly among Workgroups focused on Overarching Issues.

**Evaluation of the Role of OCCP**

The close working relationship between the Task Force and the OCCP has proven highly effective. The rapid advancement of the NJ-CCCP under the direction of the Task Force has been facilitated by the OCCP and related NJDHSS offices. Continued support for the OCCP, which is instrumental in prioritizing, coordinating, and providing structure for statewide activities, is critical for further progress.

The Executive Director of the OCCP has demonstrated effective leadership, integrating the activities of the many volunteers and organizations within the framework set by the NJ-CCCP, the Task Force, and NJDHSS. The report from the CDC site visit team acknowledged that New Jersey has become a leader nationally in comprehensive cancer control. The leadership of OCCP should be maintained.

<sup>o</sup> Extensive information on some of the activities in support of the NJ-CCCP can be found at [www.umdnj.edu/evalcweb/](http://www.umdnj.edu/evalcweb/).

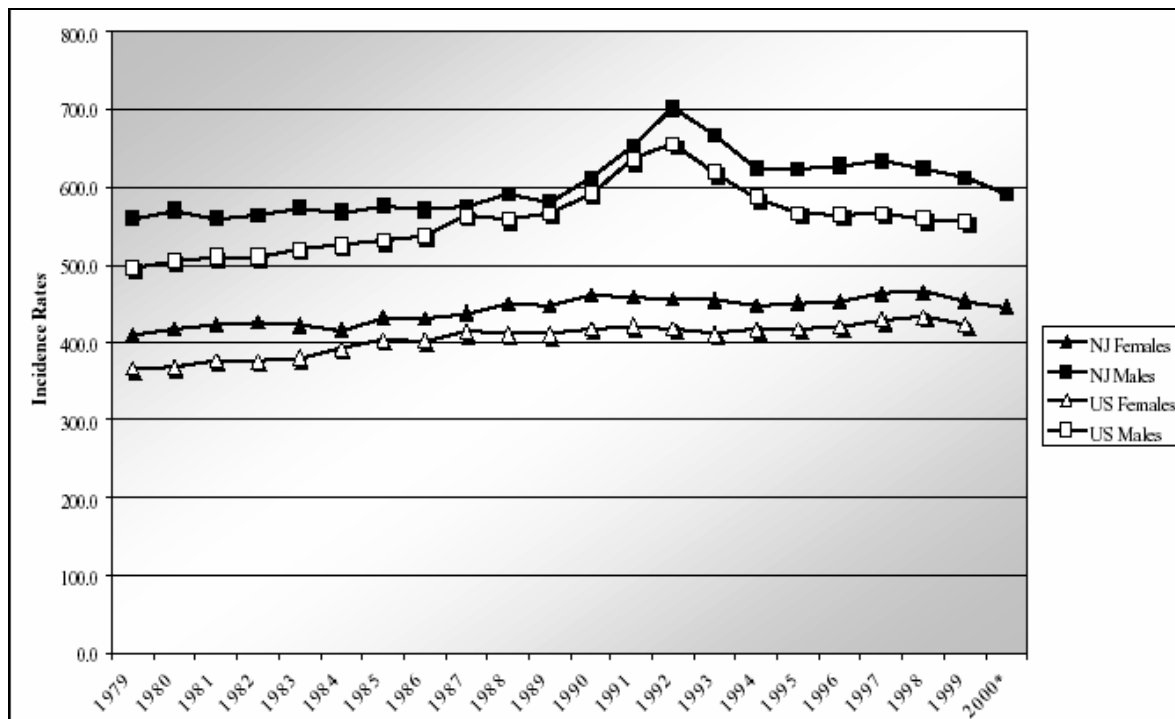
## Section 2 – Current Statewide Cancer Statistics

### Historical Trends and Overall Cancer Statistics, as Compared to the United States Overall

#### Incidence

In New Jersey, the annual incidence rate<sup>a</sup> for all cancer sites combined (among both males and females) in 2001 was 520.4 per 100,000. According to the NCI/CDC State Cancer Profiles<sup>b</sup>, this was 12% higher than the most recent U.S. rate available (for 2000). Only one state had a higher rate than New Jersey.

**U.S. and New Jersey Age-Adjusted Incidence Rates,  
All Cancer Sites, 1979–2000<sup>c</sup>**



<sup>a</sup> Incidence rates (cases per 100,000 population per year) are age-adjusted to the 2000 U.S. standard population by 5-year age groups. Rates are for invasive cancer only, unless otherwise specified

<sup>b</sup> Incidence rates reflect the most currently available data provided by the National Cancer Institute's (NCI's) and Centers for Disease Control and Prevention's (CDC's) joint State Cancer Profiles web site (accessible at <http://statecancerprofiles.cancer.gov/>), which as of December 2004 were the year 2000 for the U.S. and 2001 for New Jersey. The underlying sources of these data are the New Jersey State Cancer Registry and the National Program of Cancer Registries Cancer Surveillance System (NPCR-CSS), CDC, January 2003 data submission, as published in *United States Cancer Statistics*, November 2003; SEER November 2003 submission. The rates in those sources involve calculations using SEER\*Stat. Population counts for denominators are based on Census populations as modified by NCI.

<sup>c</sup> Source: New Jersey State Cancer Registry and SEER, as published in the NJ-CCCP. Rates are per 100,000 and age-adjusted to the 2000 U.S. population standard. Incidence rates for the year 2000 data shown in this graph were preliminary, as 2000 data were not available from SEER at the time this graph was generated.

.....

*Males:* Among males of all races, the overall cancer incidence rate in New Jersey in 2001 (629.4 per 100,000) was the second highest in the U.S. and 15% higher than the U.S. rate in 2000 (546.9 per 100,000). The annual incidence rate among white males in New Jersey (622.4 per 100,000, second highest in the U.S.) was 16% higher than the national incidence rates for white males (537.3 per 100,000). Among black males, the annual incidence rate in New Jersey (712.5 per 100,000, second highest in the U.S.) was 16% higher than the national incidence rates for black males (612.6 per 100,000) and 14% higher than white males in New Jersey. Of the eight states in the U.S. for which cancer incidence rates among Hispanic males were available, New Jersey had the highest rate (the states' incidence rates ranged from 333.9 per 100,000 to New Jersey's 525.8 per 100,000).

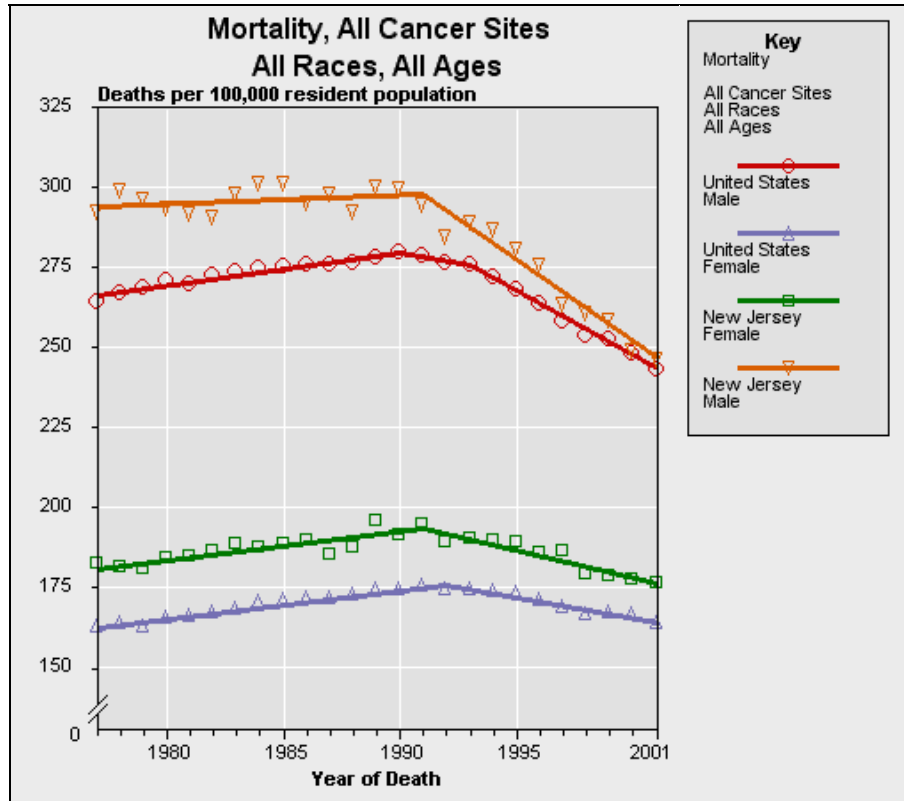
*Females:* Among females of all races, the annual incidence rate of cancer in New Jersey in 2001 (448.2 per 100,00) was the second highest in the U.S. and 10% higher than the U.S. rate in 2000 (409.4 per 100,000).

*[This section, "Historical Trends and Overall Cancer Statistics, as Compared to the United States Overall," is continued on the next page to preserve continuity of text and graphs.]*

## Mortality

In 2001, the annual cancer mortality rate in New Jersey (203.0 per 100,000) was the 18<sup>th</sup> highest state in the nation – similar to the national rate (195.6 per 100,000). The mortality rate among New Jersey blacks (242.0 per 100,000) was 20% higher than the rate among New Jersey whites (202.5 per 100,000), a pattern also seen nationwide. Although New Jersey has consistently had higher cancer mortality rates than the U.S. for over 25 years, the gap is steadily narrowing.

### U.S. and New Jersey Age-Adjusted Mortality Rates, All Cancer Sites, 1977–2001<sup>d</sup>



**Males:** For overall cancer mortality, New Jersey ranks 25<sup>th</sup> in the U.S. among males of all races, with an annual mortality rate (246.2 per 100,000) similar to the national rate (243.5 per 100,000). The mortality rate among black males in New Jersey (330.8 per 100,000) is 36% higher than the rate among white males in New Jersey (242.5 per 100,000), similar to the national pattern.

<sup>d</sup> National Cancer Institute and Centers for Disease Control and Prevention. State cancer profiles. Interactive graphs and maps: Historical trends, accessed 12/20/04. (Continually updated data may be obtained from <http://statecancerprofiles.cancer.gov/>, a site associated with <http://cancercontrolplanet.cancer.gov/>.) Underlying sources of data: Regression lines calculated using the [Joinpoint Regression Program](#). Death data provided by the [National Vital Statistics System](#) public use data file. Death rates calculated by the National Cancer Institute using [SEER\\*Stat](#). Death rates are age-adjusted to the 2000 U.S. standard population by 5-year age groups. Population counts for denominators are based on Census populations as [modified](#) by NCI. Surveillance, Epidemiology, and End Results (SEER) Program data are explained at [www.seer.cancer.gov](http://www.seer.cancer.gov).



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*Females:* For overall cancer mortality, New Jersey ranks sixth highest in the U.S. among females of all races. Among white females, New Jersey had the fifth highest mortality rate (178.0 per 100,000) of the 50 states in overall cancer mortality, which is 9% higher than the corresponding national rate (163.2 per 100,000). The annual mortality rate among black females in New Jersey (190.7 per 100,000) is 7% higher than the rate among white females in New Jersey.

### ***Commentary on the Comparison of New Jersey to National Statistics***

In summary, New Jersey has consistently had higher cancer mortality rates than the U.S. for over 25 years, although this gap is steadily narrowing. In contrast, the gap in incidence has persisted over time. Furthermore, the incidence rates in men and in women have risen from 1979 to 2001. With the introduction of screening programs, an increase in detection of cancer is expected, with the hope of a shift toward an earlier stage of diagnosis. A compensatory decrease in detection may follow in subsequent years. Since most cancers in New Jersey remain diagnosed at non-localized stages, and given the persistent gap in incidence, the high incidence rate in New Jersey does not appear to be attributable to the impact of screening. It does, in part, reflect the disproportionately high incidence of many cancers in blacks, highlighting the importance of attention to correcting disparities.

The discrepancy in improvement between cancer mortality and cancer incidence suggests a need to emphasize funding for comprehensive cancer control efforts, including tobacco control. Given the high incidence of cancer and its impact on the residents of New Jersey, cancer should remain a high priority and the State Government should increase funding to combat cancer.

### **Summary of Statewide Cancer Statistics, 1996–2000**

The time periods for the data used in this report and in the County Cancer Capacity and Needs Assessments were fixed, and were chosen to establish a uniform baseline across all counties and to enable comparison to statewide data and facilitate future assessments.<sup>e</sup>

A total of 45,249 cases of invasive cancer diagnosed in 2000 among New Jersey residents were reported to the New Jersey State Cancer Registry (NJSCR).

In New Jersey, during the period 1996–2000, the average annual age-adjusted incidence rate of all cancer was 628.7 per 100,000 among males and 453.7 per 100,000 among females.<sup>f</sup> Of all cancers, 64% of incident cases among males and 61% among females were attributed to the NJ-CCCP priority cancers. During the same time period, the average annual age-adjusted

<sup>e</sup> At the time cancer epidemiologic data were compiled for the detailed, 300- to 500-page County Capacity and Needs Assessments, the most recent five-year data available were for 1996–2000. Because of the need to remain consistent with these reports, data from this period are used herein. The Evaluation Committee recognizes, however, that a mechanism for periodic updating of these data and concomitant review and adjustment of cancer control activities, both statewide and at the county level, would be valuable. However, substantial resources to support efforts by the Evaluation Committee and the NJDHSS would need to be identified for implementation.

<sup>f</sup> New Jersey State Cancer Registry, New Jersey Department of Health and Senior Services. Cancer incidence in New Jersey by county, 1996–2000, for the New Jersey Comprehensive Cancer Control Plan county capacity/needs assessments. Personal communications to SH Weiss. August and September, 2003.

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mortality rate due to all cancers among males was 261.1 per 100,000;<sup>g</sup> 55% of the deaths were due to the NJ-CCCP priority cancers. Among females, the average annual age-adjusted mortality rate due to all cancers was 30% lower than the rate among males – 181.6 per 100,000.<sup>g</sup> The proportion attributed to the NJ-CCCP priority cancers was similar (54%).

However, based on the prevalence estimate described in Appendix I, there were approximately 50% more females than males living with a diagnosed cancer at any point in time during the period 1996–2000 (an estimated 192,000 females, as compared to 126,000 males). Possible explanations may be the difference in the types of cancer affecting females and males, a tendency for females to have longer survival than males even after adjustment for cancer site and stage, the population ratio of females to males in New Jersey (51.5% female to 48.5% male)<sup>h</sup>, and the difference in the age distribution among females and males (the median age is 38.0 years for females and is 35.5 years for males; 31.1% of the female population, but only 26.2% of the male population, is aged 50 and over; there are almost 80% more females than males aged 75 and over)<sup>h</sup>.

Among males in New Jersey, prostate cancer (incidence rate of 194.3 per 100,000) was the most common type of cancer, accounting for 49% of the NJ-CCCP priority cancers.<sup>f</sup> However, lung cancer was the leading cause of cancer death among males, accounting for 53% of the NJ-CCCP priority cancer deaths. Among New Jersey males alone, there was an average of 2,652 deaths due to lung cancer per year during the period 1996–2000 (average annual mortality rate of 74.8 per 100,000).<sup>g</sup> Due to the lack of effective screening methods to detect lung cancer at an early stage and the limited efficacy of treatment for advanced lung cancer, the survivorship of lung cancer is shorter than for many other cancers. This also explains why the prevalence of lung cancer is low. The most prevalent cancer among New Jersey males is prostate cancer, which in many men is a slow-growing cancer. Early-stage prostate cancer has virtually 100% five-year survival (see Appendix K). It is estimated that prostate cancer affected approximately 50,000 males at any point in time during the period 1996–2000 (roughly three-fifths of the estimated 83,000 males affected by one of the NJ-CCCP priority cancers during this same period).

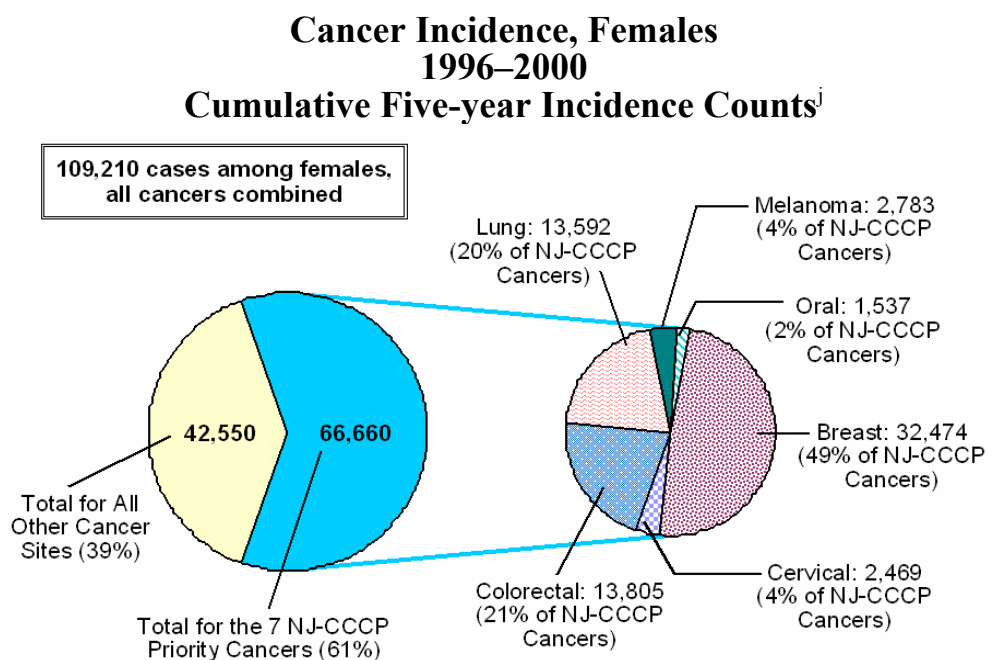
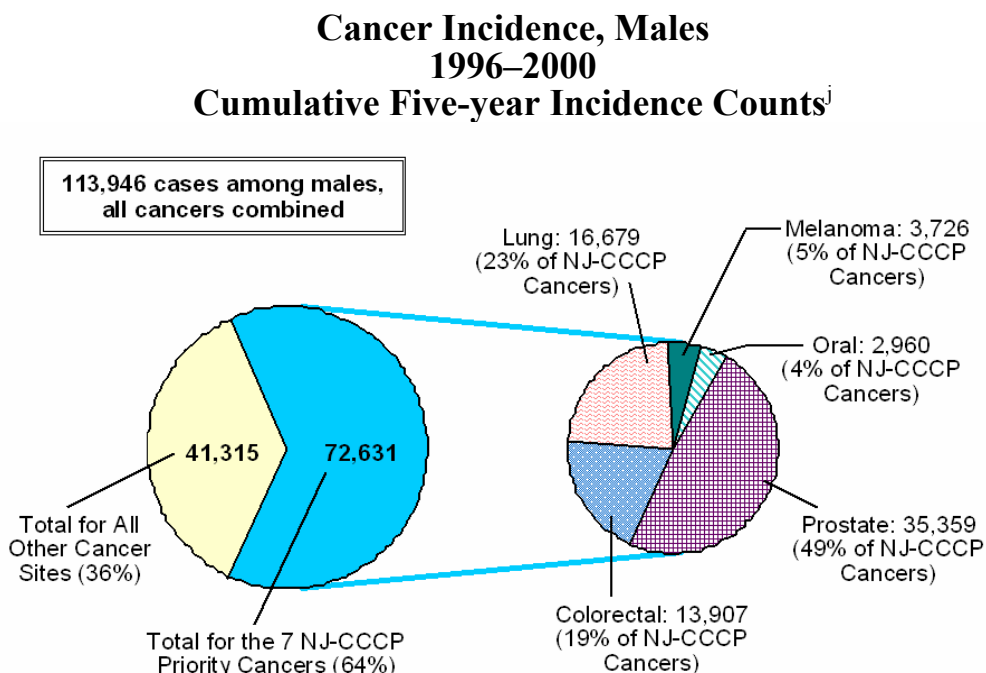
Among females in New Jersey, breast cancer (incidence rate of 138.5 per 100,000) was the most common type of cancer, accounting for 49% of the NJ-CCCP priority cancers, and was the second leading cause of cancer death among females.<sup>f,g</sup> Lung cancer, as with males, was the leading cause of cancer death among New Jersey females, responsible for 2,070 deaths on average per year (average annual mortality rate of 41.6 per 100,000).<sup>g</sup> Breast cancer was the most prevalent type of cancer among females, with an estimated 74,000 females living with diagnosed breast cancer at any point in time during the period 1996–2000; five-year survival is comparatively high for local and regional stage breast cancer (see Appendix K).

<sup>g</sup> National Cancer Institute and Centers for Disease Control and Prevention. State cancer profiles. Comparison tables: Death rates, accessed 12/20/04. (Continually updated data may be obtained from <http://statecancerprofiles.cancer.gov/>, a site associated with <http://cancercontrolplanet.cancer.gov/>.) Underlying sources of data: Death data provided by the [National Vital Statistics System](#) public use data file. Death rates calculated by the National Cancer Institute using [SEER\\*Stat](#). Death rates are age-adjusted to the 2000 U.S. standard population by 5-year age groups. Population counts for denominators are based on Census populations as [modified](#) by NCI. Surveillance, Epidemiology, and End Results (SEER) Program data are explained at [www.seer.cancer.gov](http://www.seer.cancer.gov).

<sup>h</sup> U.S. Census Bureau; Census 2000, Summary File 1, generated using American FactFinder, [www.factfinder.census.gov/](http://www.factfinder.census.gov/).

*[This section is continued on the next page to preserve continuity of text and graphs.]*

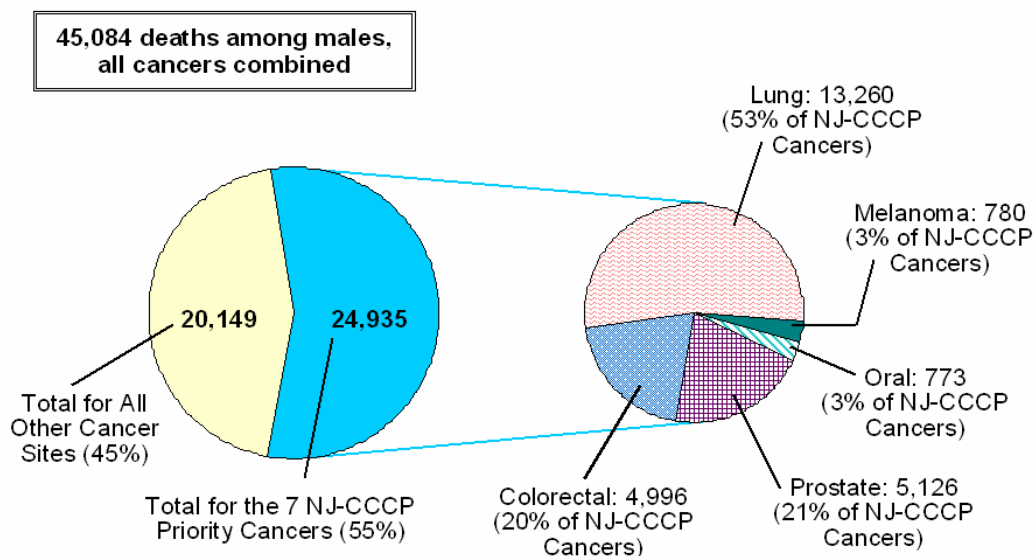
The pie charts depict both the portion of all cancers attributable to these priority cancers (left pie chart) and the respective contribution of each cancer (right pie chart).<sup>i</sup>



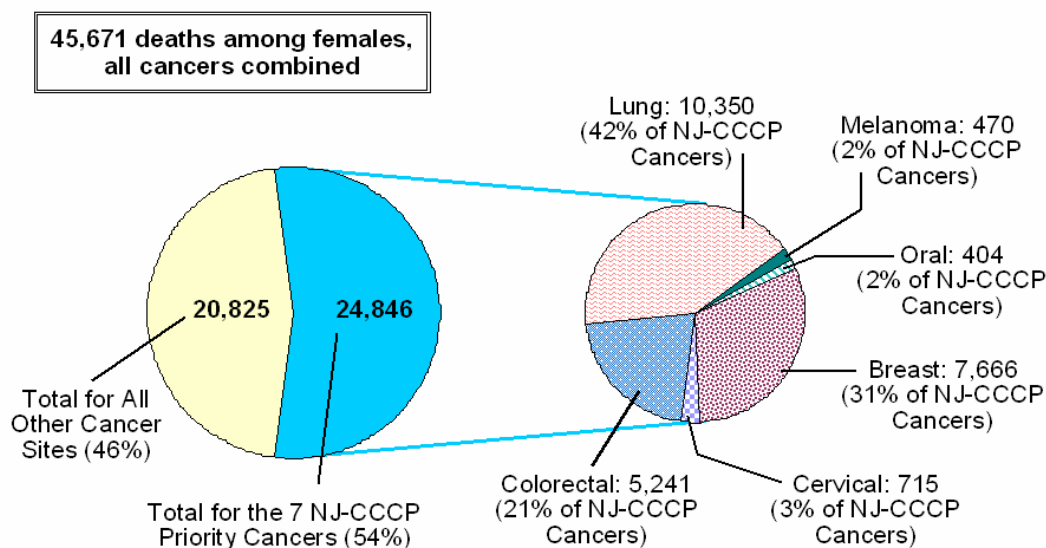
<sup>i</sup> These data are relevant to future planning efforts, as they pinpoint the proportion of cancers that are not a current focus of the NJ-CCCP. However, these other cancers will need to be evaluated individually on their own merits.

<sup>j</sup> Incidence counts provided by: New Jersey State Cancer Registry, New Jersey Department of Health and Senior Services. Cancer incidence in New Jersey, 1996–2000, for the New Jersey Comprehensive Cancer Control Plan county capacity/needs assessments. Personal communications to SH Weiss. August and September, 2003. Percentages were calculated by SH Weiss.

## Cancer Mortality, Males 1996–2000 Cumulative Five-year Mortality<sup>k</sup>



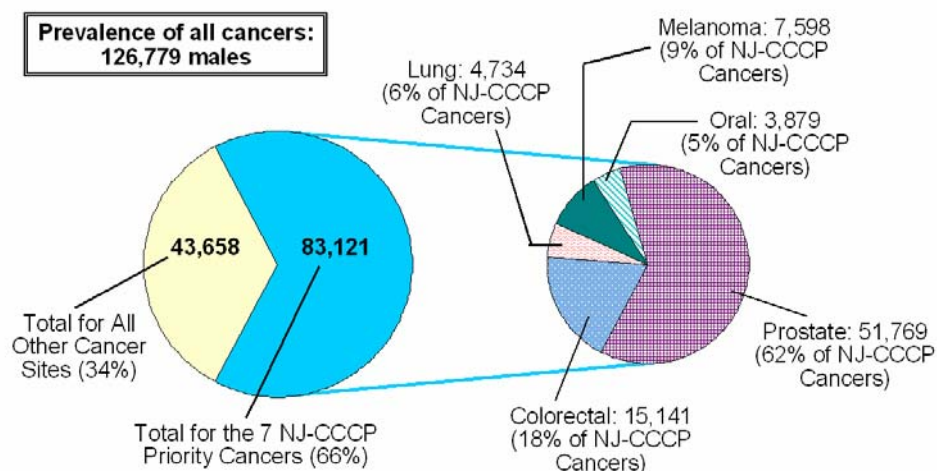
## Cancer Mortality, Females 1996–2000 Cumulative Five-year Mortality<sup>k</sup>



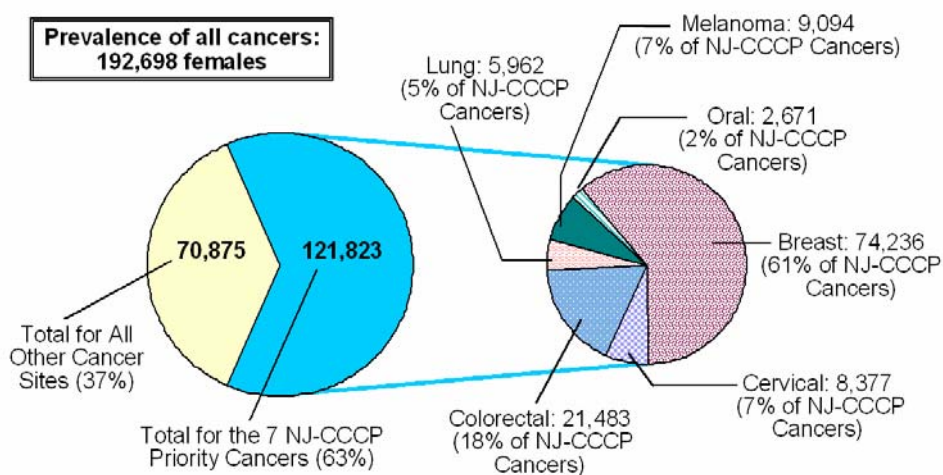
<sup>k</sup> Mortality data were provided by: Cancer Statistics Branch, Surveillance Research Program, Division of Cancer Control & Population Sciences, National Cancer Institute. Cancer mortality in New Jersey, 1996–2000, for the New Jersey Comprehensive Cancer Control Plan county capacity/needs assessments. Personal communications from M Eisner to A Tasslimi. September, 2004. Percentages were calculated by SH Weiss and staff.

See Appendix I for methodology used to calculate prevalence.  
All values shown for prevalence should be considered as rough estimates only.

### Estimated Prevalence, Males 1996–2000



### Estimated Prevalence, Females 1996–2000



## **Emerging Cancer Trend Issues**

The NJ-CCCP focuses primarily on the cancers delineated in New Jersey Executive Order 114. After issuance of that Executive Order, some important new issues emerged with respect to cancer. This led the Task Force, shortly after its creation, to expand its Workgroups, and later on to include the Emerging Trends chapter in the NJ-CCCP. After the NJ-CCCP was prepared, still other issues have arisen that are not addressed in the plan. These will merit attention from the Task Force in coming years and may need to be considered during the Task Force's development of the next five-year comprehensive cancer control plan.

### ***Changes in Proportions of Specific Histologic Types***

Nationally, changes appear to be occurring in the relative proportions of the various histologic types of certain cancers. These changes may reflect underlying differences in etiologies (with possible implications for risk factor modifications, such as behaviors and exposures) and also have important ramifications for treatment. Examination of these trends within New Jersey will therefore be important over the next decade. Some specific examples are discussed below.

**Lung Cancer.** There have been shifts in the proportion of squamous cell carcinoma and adenocarcinoma of the lung.<sup>1</sup> The epidemiologic patterns of lung cancer over time differ for men and women. The incidence of and proportion of patients with adenocarcinoma have been increasing. Both trends appear to have followed changes in smoking behavior. The increase in adenocarcinoma may be related to a shift from high-tar non-filter cigarettes toward low-tar filter cigarettes during the 1960s and 1970s.<sup>m</sup> Temporal analysis of New Jersey data stratified by gender and histologic type will be important to understanding the epidemiology of lung cancer in the state.

No screening test for lung cancer has so far been proven to prolong life. It is hoped that new approaches, such as low dose spiral computed tomography (CT), could become useful screening tools to detect lung cancer; efficacy will depend upon detection before a critical point<sup>n</sup>, so that intervention in the course of the disease can be effectively instituted. The feasibility of conducting a randomized trial with spiral CT has been demonstrated.<sup>o</sup> Results of randomized clinical trials to determine whether such detection will reduce lung cancer mortality will not be available for several years.

**Breast Cancer.** The incidence rates of ductal cell carcinoma of the breast have remained essentially constant from 1987–1999 in SEER registries, while lobular carcinoma rates have

<sup>1</sup> Thun MJ, Lally CA, Flannery JT, Calle EE, Flanders WD, Heath CW Jr. Cigarette smoking and changes in the histopathology of lung cancer. *J Natl Cancer Inst* 1997;89(21):1580-6. And Gazdar AF, Minna JD. Editorial: Cigarettes, sex, and lung adenocarcinoma. *J Natl Cancer Inst* 1997(21);89:1563-64.

<sup>m</sup> Janssen-Heijnen MLG, Coebergh JWW. Trends in incidence and prognosis of the histological subtypes of lung cancer in North America, Australia, New Zealand and Europe. *Lung Cancer* 2001;31:123-137.

<sup>n</sup> Sackett DL, Haynes RB, Guyatt GH, Tugwell P. Clinical epidemiology: A basic science for clinical medicine. Second Edition. Chapter 5, Early diagnosis. Little, Brown and Company. 1991.

<sup>o</sup> Gohagan J, Marcus P, Fagerstrom R, Pinsky P, Kramer B, Prorok P for The Lung Screening Study Research Group. Baseline findings of a randomized feasibility trial of lung cancer screening with spiral CT scan vs chest radiograph. The Lung Screening Study of the National Cancer Institute. *Chest*. 2004;126:114-121.

increased steadily.<sup>p,q</sup> “This increase presents a clinical challenge given that lobular carcinoma is more difficult to detect than ductal carcinoma by both physical examination and mammography.”<sup>p</sup> Lobular carcinoma involves both breasts more frequently than other histologic types.

Several studies have suggested that the increased risk of tumors with lobular histologies may be associated with combined estrogen and progestin hormone replacement therapy.<sup>p</sup> There remains a need to further determine the effects of progestin, as well as estrogen, on mammary tissue. The pooled analysis of 51 epidemiological studies<sup>r</sup> plus a number of more recent studies indicate that continuous combined hormonal replacement therapy (CHRT) is related to an increased risk of developing breast cancer. The results of the Women’s Contraceptive and Reproductive Experience (CARE) Study and others indicate the resulting tumors are more likely to be of lobular or mixed lobular-ductal histology,<sup>s</sup> types of breast cancer with more favorable prognosis than ductal tumors.<sup>t</sup> Women who use hormone replacement therapy (HRT) have tumors with good prognostic factors (*i.e.*, lobular histology, small tumor size, earlier stage, and estrogen/progestin receptor positivity).<sup>u</sup> These better prognostic characteristics make it more likely that women who have used HRT will have lower mortality than those women who have not used HRT. However, this advantage may in part be due to the racial and age differences in those who use the various regimens of HRT and the effect of more frequent screening among HRT users, leading to earlier diagnosis.<sup>u</sup>

These new data suggest the need to examine New Jersey breast cancer data more closely to assess the extent to which these national trends may be appearing within New Jersey. Important challenges for the coming years may include detecting and treating breast cancers of lobular histology, which are projected to increase in number based upon the high rates of hormone replacement therapy over the past few decades.

### ***Other Emerging Issues and Trends in Incidence and/or Mortality of Specific Cancers***

**Cancers of the Kidney and Renal Pelvis.** There are long-term increasing trends in incidence and mortality in New Jersey for cancers of the kidney and renal pelvis in females, although these

<sup>p</sup> Li CL, Anderson BO, Daling JR, Moe RE. Trends in incidence rates of invasive lobular and ductal breast carcinoma. Brief Report. *JAMA* 2003;289:1421-1424.

<sup>q</sup> *Infiltrating ductal carcinoma.* This is an invasive breast cancer that penetrates the wall of a duct. It historically comprised between 70% and 80% of all breast cancer cases in the U.S.

*Infiltrating lobular carcinoma.* This is an invasive cancer that has spread through the wall of a breast lobule. It may sometimes appear in both breasts, sometimes in several separate locations. It historically had accounted for between 10% and 15% of all breast cancers.

<sup>r</sup> Collaborative Group on Hormonal Factors in Breast Cancer. Breast cancer and hormone replacement therapy: collaborative reanalysis of data from 51 epidemiologic studies of 52,705 women with breast cancer and 108,411 women without breast cancer. *Lancet* 1997;350:1047-1059.

<sup>s</sup> Daling JR, Malone KE, Doody DR, et al. Relation of regimens of combined hormone replacement therapy to lobular, ductal, and other histologic types of breast carcinoma. *Cancer* (Phila.) 2002;95:2455-2465.

<sup>t</sup> Li CI, Moe RE, Daling JR. Risk of mortality by histologic type of breast cancer among women aged 50–79 years. *Archives of Internal Medicine* 2003;163:2149-2153.

<sup>u</sup> Daling JR, Malone KE, Doody DR, et al. Association of regimens of hormone replacement therapy to prognostic factors among women diagnosed with breast cancer aged 50–64 years. *Cancer Epidemiology Biomarkers & Prevention* 2003;12: 1175-1181.



mortality rates are similar to national rates.<sup>v</sup> However, during the five-year period 1997–2001, there has been a slow decline in mortality from cancers of the kidney and renal pelvis in females and males New Jersey. Given the limited numbers involved, it will be important to continue to monitor the direction of these trends, since relatively small changes from year to year in the number of cases may unduly influence five-year trend analysis.

**Cancers of the Liver and Bile Duct.** There are long-term increasing trends in mortality in males in New Jersey, as in the nation as a whole. From 1977 to 1999 there were long-term increasing trends in incidence nationally for both men and women, and the 2001 incidence rate among males in New Jersey exceeded the 2000 rate among males nationwide.

Evidence of increasing incidence of hepatocellular carcinoma (a primary cancer of the liver) attributable to infection with hepatitis viruses continues to accumulate.<sup>w</sup> It will be necessary to initiate or expand programs to monitor and treat hepatocellular carcinoma.

**Bladder Cancer.** Bladder cancer remains a leading cause of cancer deaths nationally. From 1977 to 2001, the New Jersey mortality rate due to bladder cancer, although falling, has continued to exceed the national rate.<sup>x</sup> Research studies based in New Jersey had uncovered evidence of environmental risk factors for bladder cancer<sup>y</sup>, but bladder cancer has not been a recent focus of attention in New Jersey. Long-term incidence and mortality data should be examined for each county. If there are some persistent regional differences within New Jersey, additional study may be of interest.

**Thyroid Cancer.** Recent data indicate a statistically significant rise of 17% per year in the thyroid cancer incidence rate among females in New Jersey from 1997 through 2001.<sup>z</sup> Thyroid cancer incidence among males rose 8.7% per year over the same period, although this did not reach statistical significance.<sup>z</sup> The number of new cases of thyroid cancer in New Jersey was 842

<sup>v</sup> National Cancer Institute and Centers for Disease Control and Prevention. State cancer profiles. Comparison tables: Rate/trend comparisons by state/county, accessed 12/20/04. (Continually updated data may be obtained from <http://statecancerprofiles.cancer.gov/>, a site associated with <http://cancercontrolplanet.cancer.gov/>.) Underlying sources of data: Death data provided by the National Vital Statistics System public use data file. Death rates calculated by the National Cancer Institute using SEER\*Stat. Death rates are age-adjusted to the 2000 U.S. standard population by 5-year age groups. Population counts for denominators are based on Census populations as modified by NCI.

<sup>w</sup> See Chapter 13 of the NJ-CCCP for details. Evolving new data from UMDNJ-University Hospital in Newark demonstrate a continuing rise in cases (personal communication from Lawrence Harrison, MD, 2004).

<sup>x</sup> Analysis of data from 1968 to 1977 revealed a statistically significant association between bladder cancer mortality in individual New Jersey counties and the percentage of the adult population working in the chemical industries. Najem GR, Louri DB, Najem AZ. Bladder cancer mortality in New Jersey counties, and relationship with selected environmental variables. *International Journal of Epidemiology*. 1984; 13(3): 273-280.

<sup>y</sup> Schoenberg J, Stemhagen A, Mogielnicki AP, Altman R, Mason TJ. A case-control study of bladder cancer in New Jersey. I. Occupational exposures in white males. *Journal of the National Cancer Institute*. 1984; 72:973-981.

<sup>z</sup> National Cancer Institute and Centers for Disease Control and Prevention. State cancer profiles. Interactive graphs and maps: 5-year rate changes, incidence, accessed 12/20/04. (Continually updated data may be obtained from <http://statecancerprofiles.cancer.gov/>, a site associated with <http://cancercontrolplanet.cancer.gov/>.) Underlying sources of data: The Annual Percent Change over the 5-year period was calculated by SEER\*Stat. Incidence data provided by SEER Program. Rates calculated by the National Cancer Institute using SEER\*Stat. Rates are age-adjusted to the 2000 U.S. standard population by 5-year age groups. Rates are for invasive cancer only, unless otherwise specified. Population counts for denominators are based on Census populations as modified by NCI.

in 2001.<sup>aa</sup> During the period 1997–2001, the mortality rose by 27% per year in males and decreased by 2.5% per year in females.<sup>bb,cc</sup> Although there has been much speculation concerning the rise in incidence in thyroid cancer observed nationally, much further study is needed. Among the possible reasons behind the observed increase are: improved methods for detection; exposure to therapeutic, diagnostic, and low-level environmental radiation; and other environmental exposures. The complex issues related to thyroid cancer need to be monitored.

**Lymphomas.** From 1997–2001 in New Jersey Non-Hodgkin lymphoma mortality declined 3.8% per year and incidence declined 1.4%.<sup>z,bb</sup> Although the number of new cases and of deaths per year among men and women in New Jersey are similar, the age-adjusted incidence and mortality rates are higher among men.<sup>dd</sup> Given the high HIV prevalence in New Jersey and the association between HIV and certain lymphomas, continuing attention to lymphomas is suggested.

**Ovarian Cancer.** Screening methodologies for the early detection of ovarian cancer continue to receive much attention but remain controversial given their current limitations as reflected by assessment of sensitivity, specificity, and predictive value and by the failure to demonstrate improvement in survival.

**Prostate Cancer.** A prospective cancer prevention trial was conducted using anti-androgen therapy. Interpretation of the results remains complex and controversial; although there was a statistically significant decrease in new prostate cancers among those men taking finasteride compared to controls, there was an increase in the most advanced cancers.<sup>ee</sup> Further data from analyses of histologies are expected in 2005. Androgen deprivation therapy has some adverse consequences.<sup>ff</sup> Since only 4% of the participants in the prevention trial were black, the efficacy among black men is uncertain. Nevertheless, these trial data offer the hope that there may be major changes in approaches to prostate cancer control over the next few years.

<sup>aa</sup> National Cancer Institute and Centers for Disease Control and Prevention. State cancer profiles. Comparison tables: Incidence rates, accessed 12/20/04. (Continually updated data may be obtained from <http://statecancerprofiles.cancer.gov/>, a site associated with <http://cancercontrolplanet.cancer.gov/>.) Underlying sources of incidence data: Surveillance, Epidemiology, and End Results (SEER) data, with rates calculated using SEER\*Stat. Population counts for denominators are based on Census populations as modified by NCI. SEER Program data are explained at [www.seer.cancer.gov](http://www.seer.cancer.gov).

<sup>bb</sup> National Cancer Institute and Centers for Disease Control and Prevention. State cancer profiles: Interactive graphs and maps. 5-year rate changes: mortality, accessed 12/20/04. (Continually updated data may be obtained from <http://statecancerprofiles.cancer.gov/>, a site associated with <http://cancercontrolplanet.cancer.gov/>.) Underlying sources of data: The Annual Percent Change over the 5-year period was calculated by SEER\*Stat. Death data provided by the National Vital Statistics System public use data file. Death rates calculated by the National Cancer Institute using SEER\*Stat. Death rates are age-adjusted to the 2000 U.S. standard population by 5-year age groups. Population counts for denominators are based on Census populations as modified by NCI.

<sup>cc</sup> Neither of these reached statistical significance.

<sup>dd</sup> New Jersey State Cancer Registry, Center for Cancer Initiatives, New Jersey Department of Health and Senior Services. New Jersey Cancer incidence and mortality in New Jersey, 1998–2002. <http://www.state.nj.us/health/cancer/statistics.htm>.

<sup>ee</sup> Thompson IM, Goodman PJ, Tangen CM, et al. The Influence of Finasteride on the Development of Prostate Cancer. *N Engl J Med* 2003 Jul 17;349(3):215-24. Epub 2003 Jun 24.

<sup>ff</sup> Nishiyama T, Ishizaki F, Anraku T, Shimura H, Takahashi K. The influence of androgen deprivation therapy on metabolism in patients with prostate cancer. *J Clin Endocrinol Metab*, February 2005;90:657-660.

Screening men for serum prostate specific antigen (PSA) has limited sensitivity<sup>gg</sup> and specificity and has not been demonstrated to prolong survival. Newer approaches that may have promise include monitoring for the rate of change in PSA levels and the development of more specific and/or sensitive assays.

**Colorectal Cancer.** The incidence and mortality of colorectal cancer are higher in blacks than in whites. The mean age of development in blacks is younger than in whites. Given the high incidence and younger age at presentation of colorectal cancer in blacks, the American College of Gastroenterology has proposed a change in colorectal cancer screening guidelines, with screening in blacks beginning at age 45 rather than at age 50.<sup>hh</sup> This proposal merits consideration by the NJDHSS and, in particular, the NJCEED program.

<sup>gg</sup> Thompson IM, Pauler DK, Goodman PJ, et al. Prevalence of Prostate Cancer among Men with a Prostate-Specific Antigen Level less than or equal to 4.0 ng per Milliliter. *N Engl J Med* 2004;350(22):2239-2246. Correction in *N Engl J Med* 2004;351(14):1470.

<sup>hh</sup> Agrawal S, Bhupinderjit A, Bhutani MS, et al. Colorectal cancer in African Americans. *Am J Gastroenterol* 2005;100:515-523.

## Section 3 – Status of the NJ-CCCP

This section describes the structure of the printed NJ-CCCP, its conversion to an electronic database, its functions and reporting capabilities, and a summary of progress for the strategies contained in the NJ-CCCP. A detailed report providing the status and accomplishments for all tasks relevant to each of the 319 strategies in the NJ-CCCP can be found in Appendix N.

Each Workgroup developed an action plan, laying the groundwork for implementation of the NJ-CCCP. Goals and target dates for completion were included in the action plans, with each Workgroup responsible for evaluating the progress of each strategy defined in its action plan. The Office of Cancer Control and Prevention (OCCP) and its partners – the 350 organizations and individuals who had assisted in development of the NJ-CCCP – set about implementing it. In so doing, they have become the “principal change agents” who together are assisting in addressing disparities in the cancer burden and in reducing the illness, death, and loss of productivity due to cancer in the State of New Jersey. The electronic database version of the NJ-CCCP is designed as a tool to support implementation of the NJ-CCCP and monitoring of progress. The structure of the NJ-CCCP and how it relates to the database derived from it are described briefly below.

### Organization of the NJ-CCCP

The NJ-CCCP is divided into three sections:

| <i>Section</i>  | <i>Chapter</i> | <i>Name</i>                     | <i>Chapter Label</i> |
|---|----------------|---------------------------------|----------------------|
| <b>I. Overarching Issues</b>  | 1              | Access and Resources            | AC                   |
|   | 2              | Advocacy                        | AD                   |
|   | 3              | Palliation                      | PA                   |
|   | 4              | Nutrition and Physical Activity | NP                   |
|   | 5              | Childhood Cancer                | CC                   |
| <b>II. Site-Specific Cancers</b>                                      | 6              | Breast                          | BR                   |
|   | 7              | Cervical                        | CA                   |
|   | 8              | Colorectal                      | CO                   |
|   | 9              | Lung                            | LU                   |
|   | 10             | Melanoma                        | ME                   |
|   | 11             | Oral and Oropharyngeal          | OR                   |
|   | 12             | Prostate                        | PR                   |
| <b>III. The Future of Cancer Control and Prevention in New Jersey</b> | 13             | Emerging Trends                 | ET                   |
|   | 14             | Implementation                  | IM                   |
|   | 15             | Evaluation                      | EV                   |

Each chapter begins with a description of the issue area and the formulation of an **overall goal** to define the general direction of the chapter. The chapter is then divided into more specific **goals** based on the overall goal of the chapter. Each specific goal is subdivided into **objectives** to be achieved in attaining the goal and further into **strategies**, or specific, measurable actions that can

be undertaken to achieve a given objective. Also included in the NJ-CCCP is information about the initial **principal change agents** (PCAs) among the partners who have agreed to assume responsibility for one or more strategies, as well as **target years** when individual strategies were anticipated to be undertaken.

The hierarchical relationship between goals, objectives, and strategies provides a structural organization for the NJ-CCCP. The NJ-CCCP chapters, goals, objectives, and strategies have **labels** to permit easy referencing of the NJ-CCCP components. For example, the Breast Cancer chapter is labeled as BR. The goals within a chapter are numbered consecutively. For example, the second goal within the Breast Cancer chapter is labeled BR-2, whereas the third goal within the Access chapter is labeled AC-3. The objectives within each goal are also numbered consecutively. The second objective in the first goal of the Access chapter is labeled AC-1.2, and the first objective of the second goal of the Access chapter is labeled AC-2.1. The strategies within the objectives are numbered consecutively within their objectives. AC-3.1.3 is the third strategy within the first objective of the third goal of the Access chapter, and AC-1.2.4 is the fourth strategy within the second objective of the first goal in the Access chapter.

### Example of the NJ-CCCP Hierarchy

| CHAPTER      | AC Access and Resources  |
|--------------|--|
| OVERALL GOAL | To assure that the people of New Jersey have increased access to high-quality cancer prevention, education, detection, and treatment services, including research studies, and to provide sufficient resources to meet these needs.                                  |
| GOAL         | AC-1 To improve access to cancer-related care and resources in New Jersey, especially for those at high risk and populations in need.  |
| OBJECTIVE    | AC-1.1 To identify relevant ethnic and geographic disparities in access to cancer prevention, education, diagnostic, or treatment services that exist in any age-gender subgroup, including populations with special needs, e.g., physically challenged individuals. |
| STRATEGY     | AC-1.1.1 Review the literature and New Jersey data to identify disparities in cancer burden across populations.  |
| STRATEGY     | AC-1.1.2 Design and perform studies to explore why disparities in cancer burden exist.   |
| STRATEGY     | AC-1.1.3 Develop a communication plan to disseminate the results of the cancer burden study.   |

### Development of an Electronic Version of the NJ-CCCP, including the Database for Tracking Implementation

The NJ-CCCP (book and PDF file versions) did not contain an index. Furthermore, although it lists strategies, timelines, and principal change agents involved in the implementation of each strategy, these are not electronically linked. An electronic version of the NJ-CCCP was developed<sup>a</sup> in order to link its strategies, timelines and key parties involved in implementation of each strategy. Through searching, linking, and tracking of NJ-CCCP goals, objectives, and strategies, the electronic database supports implementation of the NJ-CCCP and monitoring of

<sup>a</sup> The idea of an electronic database was originated by Dr. Weiss, who then recommended a mechanism for implementation, which was accepted by OCCP.

progress. The strategy-tracking database allows each Workgroup to input the description and status of their tasks. Although an internet-based version was strongly desired by all parties, this was not deemed feasible due to cost and the time needed to develop such a system.

With oversight by UMDNJ-NJMS<sup>b</sup>, NJDHSS contracted with the Battelle Centers for Public Health Research and Evaluation (Battelle) for the initial development of the electronic version of the NJ-CCCP, while subsequent work and modifications were funded through UMDNJ. This electronic edition of the NJ-CCCP included a documentation manual, also prepared by Battelle. Further information on the development of the electronic database and documentation manual can be found in Appendix N.

The electronic database was designed to include reporting functionality, described further in Appendix N. Reports listing strategies associated with a specific chapter, code, principle change agent, or Workgroup can be generated. These activity reports have been used by the Workgroups both to monitor their progress internally and to update the OCCP on statewide activities related to each strategy.

### **Status and Target Year Designation**

The 14 chapters in the electronic NJ-CCCP, excluding Chapter 13, include a total of 56 goals, which in turn contain 104 objectives, to be implemented through a total of 319 strategies. No Workgroup has been established surrounding issues in Chapter 13, Emerging Trends. Strategies related to this chapter were for consideration during the next planning cycle and were not designed to be developed during the current planning cycle. Thus, these strategies were not published in the NJ-CCCP for 2003–2007, although they were developed and included in the electronic NJ-CCCP.

Each Workgroup assigned a target year for commencement of each task involved in a strategy, as well as a final target year for completion of each strategy. Strategies were assigned one or more target years in the five-year period 2003–2007 (inclusive) for completion. A sixth possible target year designation, “Ongoing,” was used for strategies that are intrinsically continual and not intended to be contained within a five-year interval. For example, Strategy AC-4.1.7, “Educate the public regarding the purpose and importance of participating in clinical trials for cancer, with special emphasis on addressing the concerns of minority populations,” has target years 2005, 2006, 2007, and ongoing.

The Workgroup evaluates the progress of the strategies for which it is responsible and any tasks required. The strategy-tracking database allows the Workgroups to input these task descriptions and statuses. Workgroups can also assign overall statuses to the strategies, although at the present stage of the evaluation process, the assignment of overall statuses to strategies is being carried out by the Evaluation Team based on the task statuses and relevant target years.

<sup>b</sup> Performed by Dr. Weiss with the assistance of Ms. Collini and Mr. Diamond.

Five possible overall strategy status designations have been defined:

- Complete is assigned to any strategy for which:
  - all tasks were completed and there were no future target years (*i.e.* the last target year was 2003 or 2004), or
  - future target years exist, but all tasks were completed to date to satisfy the requirements of the strategy.
- Ongoing–Continuing is assigned to any strategy for which at least one task was listed by the Workgroup as ongoing
- Ongoing–Recommend Dropping is assigned to a strategy for which progress has been started on all tasks but due to new or updated information, the Workgroup no longer deems completion of the strategy feasible or relevant
- No Progress–Obstacles is assigned to a strategy for which an obstacle(s) has impeded progress on all tasks but the Workgroup has deemed completion of the strategy feasible
- No Progress–Recommend Dropping is assigned to a strategy for which an obstacle(s) has impeded progress on all tasks and the Workgroup does not deem completion of the strategy feasible or relevant

Strategies with “No Information” exist when no information has been provided by the responsible body. (Note that the designation of “Ongoing” as a target year for completion is different from the designation of “ongoing” as the status of a strategy.)

After initial testing of the database in the fall of 2003, Workgroups submitted updated information in the spring and in the fall of 2004. Some Workgroups have submitted updated strategy status information only sporadically, resulting in a substantial proportion of strategies with “No Information.” Thus, this report likely underestimates the progress towards completion of the strategies. Furthermore, a delay in funding was an obstacle in the commencement of some strategies, resulting in delays in completion. Further evaluation of the progress of these strategies will be the focus of the next 18 months. New OCCP personnel hired under the CDC grant will assist Workgroups to provide updated status information on strategies on a biannual basis. It is recommended that efforts to update the status designation of strategies with “no information” should be focused initially on Workgroups that either have any strategies with a final target year of 2003 or 2004 designated with “no information” as their status (CC, BR, CE, CO, ME, OR, PR), or have more than 25% of their total strategies designated with “no information” as the status (BR, CE, CO, ME, OR).

Each individual task under a strategy has a status assigned to it. The set of statuses available for the individual tasks is larger and allows for the recording of more detail than those used for strategies. This allows recording of whether progress is on, ahead of, or behind schedule and what obstacles, if any, are present. Appendix N demonstrates the implementation of this tracking process for strategies and individual tasks.

## **Status of NJ-CCCP Strategies**

### ***Strategy Status by NJ-CCCP Target Years, as of December 2004***

The table below tabulates the status of all NJ-CCCP strategies based on the combination of the initial and final target year. Only those combinations that occur in at least one strategy are shown

(not all possible combinations of initial and final target year exist). For example, all strategies with an initial target year of 2003 have a final target year of either 2003, 2007, or Ongoing, and no strategies have an initial target year of 2006.

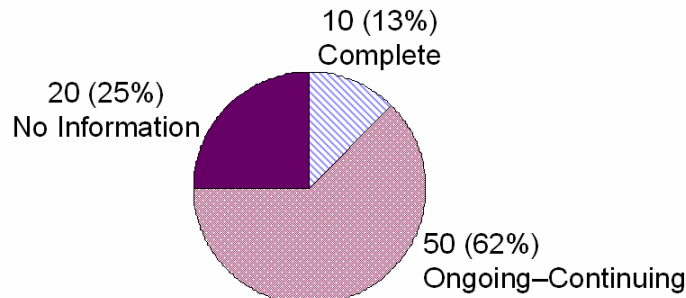
| NJ-CCCP Strategy Schedule |                   | Totals | Strategy Status as of December 17, 2004 |                      |                         |                                  |                |
|---------------------------|-------------------|--------|---|----------------------|-------------------------|----------------------------------|----------------|
| Initial Target Year       | Final Target Year |        | Complete                                | Ongoing – Continuing | No Progress – Obstacles | No Progress – Recommend Dropping | No Information |
| 2003                      | 2003              | 44     | 20%                                     | 59%                  | -                       | -                                | 20%            |
| 2004                      | 2004              | 36     | 3%                                      | 67%                  | -                       | -                                | 31%            |
| 2003                      | 2007 or Ongoing   | 73     | 4%                                      | 78%                  | -                       | 3%                               | 15%            |
| 2004                      | Ongoing           | 3      | -                                       | 33%                  | -                       | -                                | 67%            |
| 2005                      | 2005 or Ongoing   | 33     | -                                       | 76%                  | -                       | -                                | 24%            |
| 2007                      | 2007 or Ongoing   | 130    | 2%                                      | 71%                  | 5%                      | -                                | 22%            |
| Totals                    |                   | 319    | 5%                                      | 71%                  | 2%                      | 1%                               | 22%            |

**Strategy Status by Summarization of NJ-CCCP Final Target Years, as of December 2004**

Because this assessment was conducted at the end of 2004, progress on strategies with final target years of 2003 and/or 2004 was tabulated separately from strategies with a later or ongoing final target year. The two pie charts below display the status of strategies, based upon the final target year.

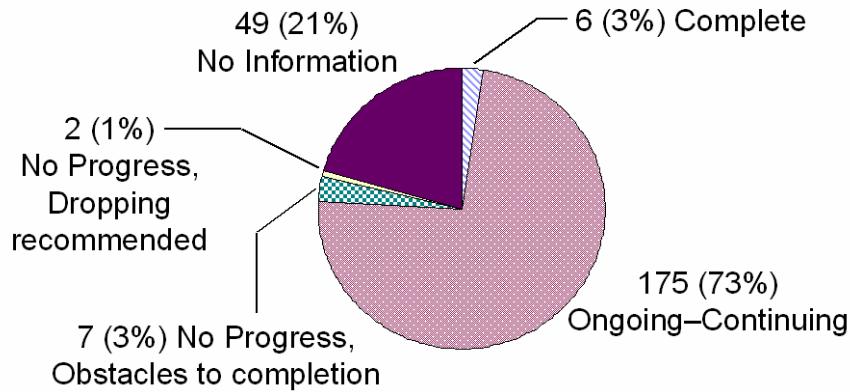
Of the 80 strategies with 2003 and/or 2004 as the target year for completion, 13% are complete, 62% are ongoing-continuing, and updated information was not provided for 25%.

**Strategies with Final Target Year: 2003 or 2004  
(n=80)**





**Strategies with Final Target Year: 2005–2007 or Ongoing\***  
(n=239)



\*Excludes strategies from the NJ-CCCP chapter on Emerging Trends (see explanation above)

***Strategy Status by NJ-CCCP Chapter, as of December 2004***

The table below summarizes the status of all NJ-CCCP strategies by chapter. A final target year of “2005-Ongoing” indicates that the final target year is one of the following: 2005, 2006, 2007, or 2007+ongoing.

| Chapter (Chapter Label)   | Final Target Year | Total Number of Strategies | Complete  | Ongoing-Continuing | No Progress-Obstacles | No Progress-Recommend Dropping | No Information Available |
|---|-------------------|----------------------------|-----------|--------------------|-----------------------|--------------------------------|--------------------------|
| <b>Section I. Overarching Issues</b>  |                   |                            |           |                    |                       |                                |                          |
| Access and Resources (AC)   | 2003              | 5                          | 2         | 3                  | -                     | -                              | -                        |
|   | 2004              | 4                          | -         | 4                  | -                     | -                              | -                        |
|   | 2005-Ongoing      | 29                         | 1         | 25                 | -                     | -                              | 3                        |
| Advocacy (AD)   | 2003              | 1                          | -         | 1                  | -                     | -                              | -                        |
|   | 2005-Ongoing      | 15                         | 1         | 14                 | -                     | -                              | -                        |
| Palliation (PA)   | 2003              | 2                          | -         | 2                  | -                     | -                              | -                        |
|   | 2004              | 2                          | -         | 2                  | -                     | -                              | -                        |
|   | 2005-Ongoing      | 4                          | -         | 3                  | -                     | -                              | 1                        |
| Nutrition and Physical Activity (NP)  | 2004              | 3                          | -         | 3                  | -                     | -                              | -                        |
|   | 2005-Ongoing      | 19                         | -         | 14                 | 2                     | 2                              | 1                        |
| Childhood Cancer (CC)   | 2003              | 5                          | -         | 4                  | -                     | -                              | 1                        |
|   | 2004              | 11                         | -         | 9                  | -                     | -                              | 2                        |
|   | 2005-Ongoing      | 9                          | -         | 7                  | -                     | -                              | 2                        |
| <b>Section II. Site-Specific Cancers</b>                                      |                   |                            |           |                    |                       |                                |                          |
| Breast Cancer (BR)  | 2003              | 4                          | -         | 2                  | -                     | -                              | 2                        |
|   | 2005-Ongoing      | 38                         | 1         | 24                 | 3                     | -                              | 10                       |
| Cervical Cancer (CE)  | 2003              | 5                          | -         | 4                  | -                     | -                              | 1                        |
|   | 2005-Ongoing      | 25                         | -         | 11                 | -                     | -                              | 14                       |
| Colorectal Cancer (CO)  | 2003              | 2                          | -         | -                  | -                     | -                              | 2                        |
|   | 2004              | 1                          | -         | 1                  | -                     | -                              | -                        |
|   | 2005-Ongoing      | 9                          | -         | 4                  | -                     | -                              | 5                        |
| Lung Cancer (LU)  | 2003              | 2                          | 1         | 1                  | -                     | -                              | -                        |
|   | 2005-Ongoing      | 15                         | 1         | 14                 | -                     | -                              | -                        |
| Melanoma (ME)   | 2003              | 2                          |           |                    | -                     | -                              | 2                        |
|   | 2004              | 3                          |           | 1                  | -                     | -                              | 2                        |
|   | 2005-Ongoing      | 22                         | 1         | 11                 | 1                     |                                | 9                        |
| Oral and Oropharyngeal Cancer (OR)  | 2003              | 3                          | 1         | 2                  | -                     | -                              | -                        |
|   | 2004              | 8                          | -         | 2                  | -                     | -                              | 6                        |
|   | 2005-Ongoing      | 19                         | -         | 15                 | -                     | -                              | 4                        |
| Prostate Cancer (PR)  | 2003              | 7                          | -         | 6                  | -                     | -                              | 1                        |
|   | 2004              | 3                          | -         | 2                  | -                     | -                              | 1                        |
|   | 2005-Ongoing      | 26                         | -         | 25                 | 1                     | -                              | -                        |
| <b>Section III. The Future of Cancer Control and Prevention in New Jersey</b> |                   |                            |           |                    |                       |                                |                          |
| Emerging Trends (ET)*   |                   |                            |           |                    |                       |                                |                          |
| Evaluation (EV)   | 2003              | 1                          | 1         | -                  | -                     | -                              | -                        |
|   | 2004              | 1                          | 1         | -                  | -                     | -                              | -                        |
|   | 2005-Ongoing      | 1                          | -         | 1                  | -                     | -                              | -                        |
| Implementation (IM)   | 2003              | 5                          | 4         | 1                  | -                     | -                              | -                        |
|   | 2005-Ongoing      | 8                          | 1         | 7                  | -                     | -                              | -                        |
| <b>All Chapters</b>   | 2003              | 44                         | 9         | 26                 | 0                     | 0                              | 9                        |
|   | 2004              | 36                         | 1         | 24                 | 0                     | 0                              | 11                       |
|   | 2005-Ongoing      | 239                        | 6         | 175                | 7                     | 2                              | 49                       |
| <b>Total</b>  |                   | <b>319</b>                 | <b>16</b> | <b>225</b>         | <b>7</b>              | <b>2</b>                       | <b>69</b>                |

\* The status of the strategies pertaining to Emerging Trends is summarized separately in the following table, as explained above.

***Status of Strategies Related to NJ-CCCP Chapter 13, Emerging Trends, as of December 2004***

For the reasons explained above, no Workgroup has been established surrounding issues in Chapter 13: access to clinical trials, cancer survivorship, complementary and alternative medicine, and infection and cancer. Strategies related to this chapter have been developed and are tabulated separately below.

| Chapter (Chapter Label)                | Final Target Year | Total Number of Strategies | Complete | Ongoing-Continuing | No Progress-Obstacles | No Progress-Recommend Dropping | No Information Available |
|--|-------------------|----------------------------|----------|--------------------|-----------------------|--------------------------------|--------------------------|
| Emerging Trends (ET)                   |                   |                            |          |                    |                       |                                |                          |
| Access to Clinical Trials              | 2005-Ongoing      | 2                          | -        | -                  | -                     | -                              | 2                        |
| Cancer Survivorship                    | 2005-Ongoing      | 6                          | -        | -                  | -                     | -                              | 6                        |
| Complementary and Alternative Medicine | 2005-Ongoing      | 3                          | -        | -                  | -                     | -                              | 3                        |
| Infection and Cancer                   | 2005-Ongoing      | 19                         | -        | 19                 | -                     | -                              | -                        |
| <b>Total (for Chapter ET only)</b>     |                   | <b>30</b>                  | <b>-</b> | <b>19</b>          | <b>-</b>              | <b>-</b>                       | <b>11</b>                |

## Section 4 –Cancer Resource Database of New Jersey (CRDNJ)

The Cancer Resource Database of New Jersey is a novel, statewide database of detailed information developed to identify resources currently available in each county for cancer screening, education, advocacy, treatment, palliation, and other activities. This section describes the design and development of the Cancer Resource Database of New Jersey, the data collection process, preparation of the data for use, and planned applications of the database.

### Development of the Database System

During the planning phases of the Capacity and Needs Assessment process, the need to systematically collect, organize, update, and analyze information on resources available in each county was identified. In response, the Cancer Resource Database of New Jersey (CRDNJ) was developed by UMDNJ-New Jersey Medical School and NJDHSS-OCCP<sup>a</sup>. Under a Memorandum of Agreement between NJDHSS and UMDNJ, the database design and process were guided by past best practices, and in particular those established by the American Cancer Society (ACS).<sup>b</sup> The CRDNJ data collection forms were designed to ensure that data were captured on web site addresses, e-mail addresses, and address information sufficient to permit coding using geographic information system software.

A key element in design was to enable persons to collect data locally in the field, where a computer might not be available, and for all data to be transmitted and maintained at a central location. Standardized data collection forms (colloquially referred to as “TELEforms”) were developed, and a new electronic database that could be used by the County Evaluators.

These TELEforms are copyrighted forms with standardized, requested data fields. Both paper versions and electronically writeable PDF files were designed to be faxed into a central location. Details on the development and functioning of this data collection system may be found in Appendix D.

### *Standardized Forms (TELEforms)*

Facility Forms – Four types of standard forms were developed to collect data on individual facilities:

- Healthcare Resources – The Healthcare Resource form is designed to capture information on a wide array of institutions and providers such as clinics, mobile units, voluntary organizations such as the ACS, and hospitals. The range of entities for which this form was used was not meant to coincide with any state or federal definitions of a healthcare

<sup>a</sup> Developed by Dr. Stanley H. Weiss, Ms. Peg Knight, and their respective staff.

<sup>b</sup> The ACS had developed a proprietary system called “E-Tool” to collect data for their own “Community Needs Assessment.” The data elements and coding from this system were critically reviewed at UMDNJ. These were substantially revised, to systematize the forms into a more limited set of separate forms, add key additional data elements, remove elements the ACS had found not to be useful, and thoroughly update the options. Suggestions were solicited from the County Evaluators (see Section 5, below), who piloted the use of draft forms, to best adapt these to their needs, as the County Evaluators were assigned the task of conducting the county-level data collection.

facility. Because of the breadth of resources it could encompass, it was the most frequently used TELEform, and it enhanced the simplicity of the system. The other types of organizations coded on the Healthcare Resource form, although not exclusively healthcare providers, are often gateways or points of entry to necessary health care services.

- Faith-Based Organizations
- Schools and School Districts
- Major Employers

Supplemental Forms – Two other types of TELEforms were designed to provide information to supplement the data recorded on the facility forms:

- Activity forms collect information about specific activities conducted by a facility; up to 99 activity forms can be linked to a single facility form.
- Comment forms, to collect freeform comments. Multiple fields were used to enable long comments because of limitations on the length of (i.e. the number of characters in) a field. These can be linked to either a facility form or to a specific activity form.

### **Collection of Cancer Resource Data by County Evaluators**

The County Evaluators were provided training on the use of TELEforms for collection of data on groups and institutions involved in cancer screening, education or treatment in their county. The goal was to develop a picture of where and for whom services are available by capturing and reporting this in each county. By focusing on and emphasizing underserved regions, County Evaluators were then able to quantitatively describe disparities between capacity and needs on a local basis.

Full ascertainment of resource data for selected types of healthcare facilities was sought. These facility types included hospitals, federally qualified healthcare centers (FQHC's), hospices, NJCEED agencies, and mammography centers. A directory of mammography providers throughout the state, divided and listed by county<sup>c</sup>, was utilized as the basis upon which to build the mammography center information.

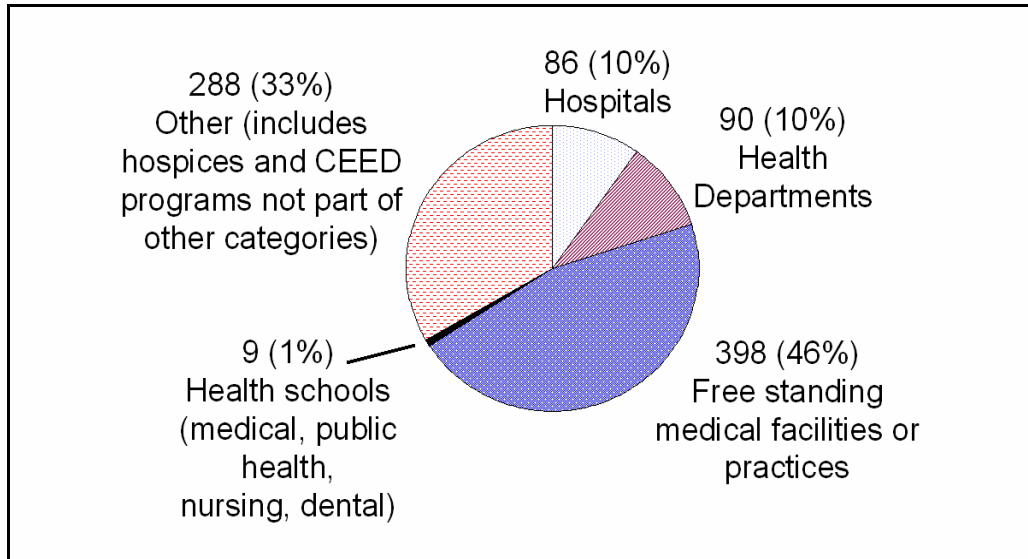
For other types of facilities, it was the responsibility of the County Evaluators to determine which other facilities were the most important to capture in the CRDNJ for their county. These could include facilities such as physician practices (e.g., gastroenterologists and others involved in colorectal cancer screening), freestanding oncology clinical practices, faith-based organizations, schools, and workplaces. Full ascertainment was not attempted for these other facility types due to funding limitations.

The CRDNJ has 2,731 facility entries (Healthcare, Schools, Faith-based Organizations, and Workplaces) and 555 supplemental form entries (Activities and Comments), with detailed data on cancer resources throughout New Jersey, as of November 30, 2004.

<sup>c</sup> The “Early Detection Saves Lives: A Guide to Breast Cancer Screening Services in New Jersey” and “Directory of Mammography Providers and County and Local Services” from the Health Research & Educational Trust (HRET) of New Jersey of the New Jersey Hospital Association. Confer <http://www.njha.com/hret/bclist.aspx>

As a result of the CRDNJ survey, information on a total of 871 healthcare resources (broadly construed) was collected. The distribution of healthcare resources, based on facility forms (supplemental forms are not included), is shown below.

**Healthcare Resources in the CRDNJ  
Based on Facility Forms  
(n=871)**



The table below shows the number of TELEforms submitted in each area and the total number of TELEforms submitted, reflecting updates to the Healthcare database coordinated by the CRDNJ Geographic Information Systems (GIS) Group as of November 30, 2004.

The “Total” column for each type of form (facility or supplemental) sums the number of forms received in each respective category: Healthcare, School, Faith, and Workplace for the category “Facility” and Activity and Comments for the category “Supplemental.”

| County | Number of TELEforms submitted in each category* |        |       |            |                      |                    |          |                          |
|--------|---|--------|-------|------------|----------------------|--------------------|----------|--------------------------|
|        | Facility Forms                                  |        |       |            | Total Facility Forms | Supplemental Forms |          | Total Supplemental Forms |
|        | Health-care                                     | School | Faith | Work-place |                      | Activity           | Comments |                          |
| ATL    | 30  | 27     | 16    | 1          | 74                   | 14                 | 12       | 26                       |
| BER    | 70  | 48     | 32    | 6          | 156                  | 55                 | -        | 55                       |
| BUR    | 59  | 82     | 29    | 27         | 197                  | 56                 | 21       | 77                       |
| CAM    | 74  | 132    | 19    | 4          | 229                  | 57                 | -        | 57                       |
| CAP    | 19  | 17     | 18    | 4          | 58                   | 6                  | 7        | 13                       |
| CUM    | 38  | 75     | 211   | 59         | 383                  | 19                 | 8        | 27                       |
| ESS    | 80  | 28     | 19    | 4          | 131                  | 97                 | -        | 97                       |
| GLO    | 26  | 24     | 2     | 2          | 54                   | 30                 | 6        | 36                       |
| HUD    | 29  | 24     | 5     | 4          | 62                   | 16                 | 4        | 20                       |
| HUN    | 67  | 47     | 104   | 40         | 258                  | 17                 | -        | 17                       |
| MER    | 75  | 10     | 35    | 72         | 192                  | -                  | 3        | 3                        |
| MID    | 29  | 25     | 41    | 46         | 141                  | 11                 | -        | 11                       |
| MON    | 54  | 59     | 55    | 47         | 215                  | 21                 | 1        | 22                       |
| MOR    | 31  | 1      | 9     | -          | 41                   | 10                 | 12       | 22                       |
| OCE    | 33  | 50     | 23    | -          | 106                  | -                  | -        | 0                        |
| PAS    | 31  | 2      | 13    | -          | 46                   | 13                 | 7        | 20                       |
| SAL    | 8   | 22     | 7     | 5          | 42                   | 1                  | -        | 1                        |
| SOM    | 46  | 20     | 11    | 15         | 92                   | 21                 | 11       | 32                       |
| SUS    | 12  | 15     | 1     | -          | 28                   | 9                  | 4        | 13                       |
| UNI    | 20  | 6      | 7     | 3          | 36                   | 5                  | 1        | 6                        |
| WAR    | 40  | 42     | 68    | 40         | 190                  | -                  | -        | 0                        |
| Total  | 871   | 756    | 725   | 379        | 2731                 | 458                | 97       | 555                      |

\* 100% ascertainment of resource data has been attempted for healthcare facilities in the following categories: hospitals, federally qualified healthcare centers (FQHCs), hospices, NJCEED agencies, and mammography centers. Centralized cross-checking of these elements of the database with external sources was performed to eliminate duplication and identify missing facilities.

### Use of CRDNJ Data

As an effort funded and created jointly from resources at UMDNJ and NJDHSS, the use of the CRDNJ data is governed by the Memorandum of Agreement under which it was created. The intent of all parties is to find uses of the database that maximally promote the public good.

### *Geographic Information Systems (GIS)*

GIS is a collection of computer hardware, software, and geographic data for capturing, storing, updating, manipulating, analyzing, and displaying all forms of geographically referenced

Components of the CRDNJ will be linked with:

- Once geocoded and linked, the data from these various files can be mapped, as appropriate, at the census tract, municipality, zip code, county, or state levels.

- The general public, including patients and their families;
- Researchers and health planners.

- Identification of geographic areas where gaps in cancer services exist
- Understanding the barriers to access among specific populations, such as transportation, lack of translation services, lack of insurance, insufficient capacity at facilities (especially screening facilities), lack of oncology services, etc.
- Allocation of funding
- Proposing where to allocate new cancer-related healthcare facilities and/or providers, such as mammography centers, FQHC's, oncology specialists, etc.
- Recommending where to direct various cancer resources, such as screening programs, support groups, culturally-sensitive messages and tailored education, etc. based on the demand, need, and sociodemographic factors.

<sup>d</sup> Organized by Dr. Weiss.

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### ***CRDNJ Collaboration with the American Cancer Society (ACS)***

The ACS maintains a national call center through which patients and healthcare providers can obtain referrals to local cancer resources. The database supporting their call center, however, has been difficult to maintain and currently has only about 300 entries for New Jersey resources. Discussions with the ACS evolved into a collaboration to use the CRDNJ database elements in their new web-based national database. New Jersey will be the first state included in pilot testing for their new web initiative. Thus, the CRDNJ data will be the source of information used by the ACS's national call center to refer callers to local resources. The ACS determined through the development of this new initiative that New Jersey is the only state with data this comprehensive and up-to-date.

### **Development of the CRDNJ GIS Group**

A working group of members with various areas of expertise<sup>f</sup> was established as described in Appendix D. Several County Evaluators are part of the CRDNJ GIS Group. An initial organizing meeting was held in September 2004.

### ***Summary of Accomplishments of the CRDNJ GIS Group***

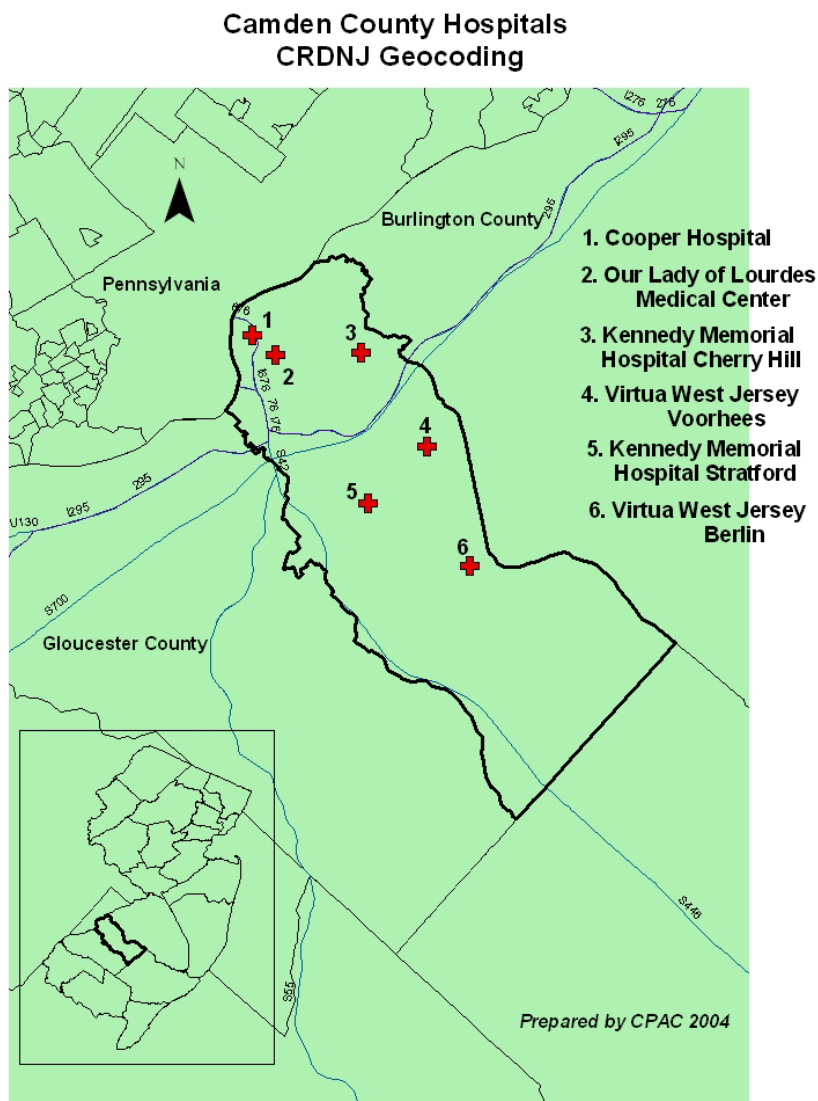
1. Uses for the CRDNJ-linked GIS, both short- and long-term were identified.
2. A plan to distill a usable data set from all data collected was developed.
3. The process for ensuring data accuracy and striving towards 100% completeness for specified areas was established.
4. A document summary, including data fields to be shared with the ACS and a description of the limitations of specific variables, was completed.
5. A prototype *interactive* map of healthcare facility resources from the CRDNJ was created, with the goal of developing maps for every county, for various types of facilities (e.g., hospitals, mammography centers, etc.), with the following elements:
  - Facility Name
  - Address (Street, City, State, Zip)
  - Telephone and Fax Number
  - Website address, if available (set up as a hyperlink)

This allows visitors to the OCCP website to locate nearby facilities and obtain information about any facility by a single mouse click. An advantage of this approach is that it links to the latest data posted by the individual facility without the need for centralized updating. The prototype was demonstrated to the Task Force at its December 6, 2004 meeting.

In order to view surrounding counties and eliminate potential confusion by visitors to the web site, a side navigation bar with the list of counties and their hyperlinks can be created; alternatively, clicking on a map of all of New Jersey might reveal the particular county and adjacent counties to facilitate finding nearby facilities across county lines. The CRDNJ GIS Group will be making decisions on these issues during 2005. The

<sup>f</sup> Led by Drs. Weiss and Mouch.

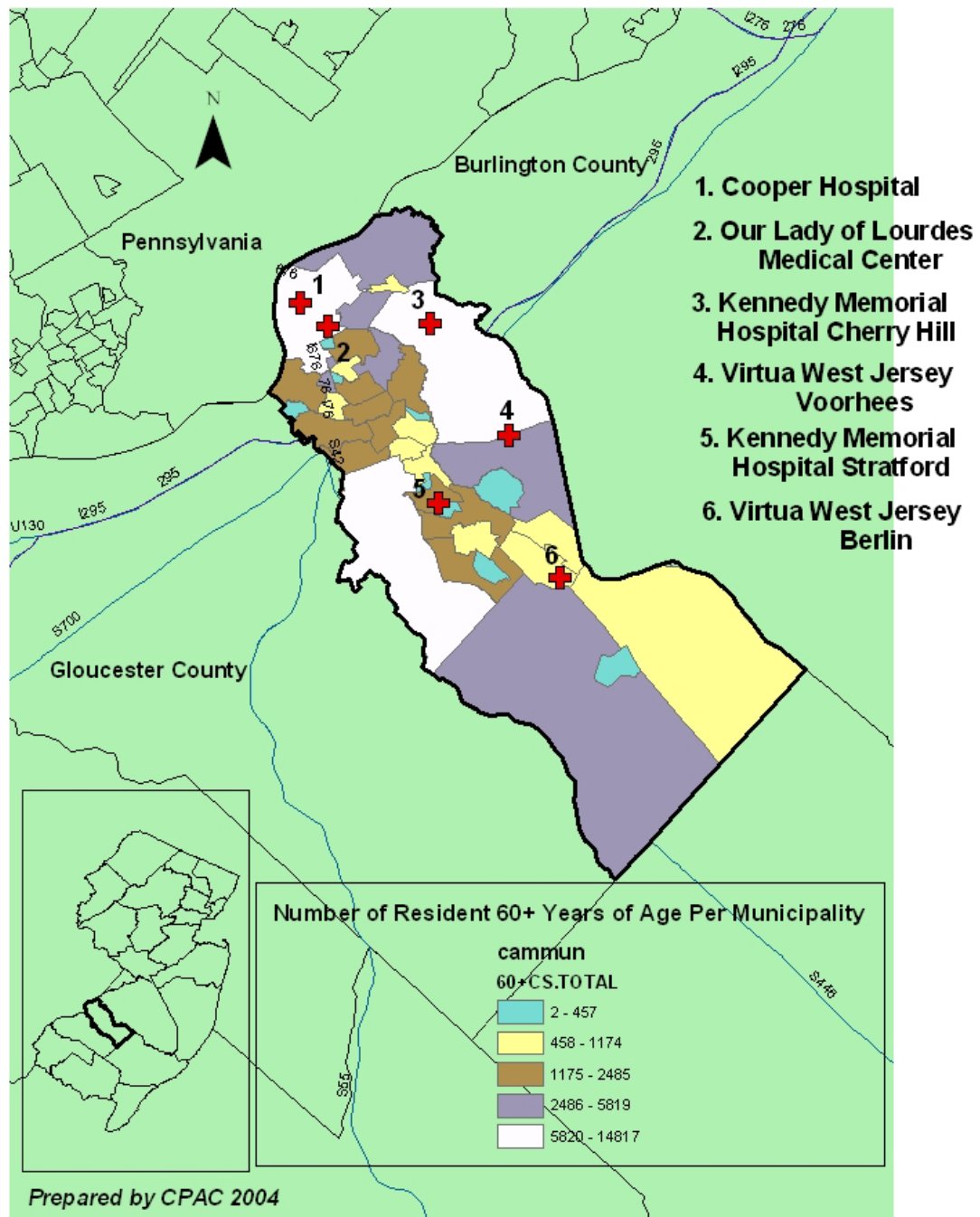
prototype below displays Camden County's neighboring counties, as well as its neighboring state of Pennsylvania; it portrays the six hospitals and some key highways located in the county. The live web page reveals the details of each hospital when the mouse pointer is moved over the hospital's icon (depicted here by a red cross).



Source: Maps provided and prepared by Mr. Robert Allen, CPAC

In the map below, the same hospital information above is now layered with demographic information. These types of maps are envisioned to be valuable for public health planning purposes. The capability to display a variety of maps is envisioned.

## Camden County Hospitals CRDNJ Geocoding



### ***Ongoing CRDNJ GIS Group Activities:***

1. Specific issues pertaining to the database software and infrastructure are under discussion, including but not limited to database maintenance, sharing of responsibility, and associated resource requirements and software knowledge.
2. The types of data to be transmitted and method of transmission to the ACS and other parties remain undetermined. An analysis of specific data fields has been undertaken by Drs. Mouch and Weiss, and issues related to confidentiality of data have been discussed extensively by the Evaluation Committee.
3. Increased sophistication of GIS analyses will be necessary to identify potential areas requiring further investigation.
4. Adding selected other important resources, for example the New Jersey QuitCenters, is under discussion.

The CRDNJ GIS Group recommends that a potential collaboration with Cancer Epidemiology Services in the NJDHSS should be explored in the near future in order to amplify analyses of cancer incidence, staging, and mortality at more local levels.

Additional information on the groups participating in the efforts and on software mentioned in this section can be found in Appendix D.

## Section 5 – Cancer Capacity and Needs Assessment

This section describes the capacity and needs assessments conducted in each county as part of the statewide initiative. A description of those conducting these assessments, training of those individuals, collaborations during this process, and the review process for the report summaries and highlights of common findings across multiple counties are provided in this section.

As one of the first implementation tasks of the NJ-CCCP, the Task Force mandated a comprehensive data-driven cancer-related capacity and needs assessment (C/NA). A C/NA was undertaken in each of New Jersey's 21 counties to identify its major cancer issues and to propose recommendations for improvement. The Cancer C/NA Report provided an analysis of (1) the county's population demographics, (2) available resources for cancer prevention, screening, and treatment, (3) cancer incidence, mortality, stage of diagnosis, and estimated prevalence for the seven priority cancers of the NJ-CCCP, as well as selected other cancers of relevance to the county, and (4) the populations of focus, causes of and solutions for the county's cancer burden. These data guided the development of evidence-based recommendations and interventions to address cancer control priorities at local and state levels. (Please see Appendices F and G for a summary of statewide and countywide cancer statistics.)

The Cancer Capacity and Needs Assessment Reports provide detailed baseline assessments for each county. The data, interpretations, and recommendations in these reports were developed to provide a wide array of public health and medical personnel with standardized information and detailed analyses that can help guide and focus their efforts at the county level, including such local health initiatives as the forthcoming Community Health Improvement Plans (see Section 6 for further information). The reports from all of the counties will collectively inform the continuing comprehensive cancer control efforts and policies of the Office of Cancer Control and Prevention (OCCP), the Task Force, and all cancer stakeholders in New Jersey. Primary responsibility for the scientific review of these assessments has been invested with UMDNJ and with the Evaluation Committee.

### Conducting the Assessment

The C/NA was conducted by a NJ-CCCP County Evaluator, funded by the OCCP through NJCEED to NJCEED's 25 agencies/programs (one or two per county). Some of the key responsibilities of the County Evaluator related to the C/NA included:

- Describing the demographic characteristics of the county and analyzing differences from statewide characteristics
- Investigation of the cancer screening capacity in the county
- Identification of key resources available to county residents for cancer screening, treatment, education, and support services
- Describing the system for early detection and prompt therapy of cancers in the county
- Working with OCCP and the New Jersey State Cancer Registry to identify communities and populations where cancer burden is highest in the county
- Identification of potential barriers to cancer screening faced by county residents

- Identification of disparities in cancer incidence, stage at diagnosis, and mortality within the county and of differences from the state's cancer epidemiology profile
- Development and prioritization of county- and state-level recommendations to reduce the burden of cancer within the county

### ***Collaborations***

Numerous entities were involved in the C/NA process:

- The New Jersey State Cancer Registry (NJSCR) provided all incidence data at several levels of analysis for all counties. In addition, the NJSCR provided epidemiologic input and training for the County Evaluators on several issues, including use of incidence data and the status of bladder cancer in New Jersey.
- Kenneth J. O'Dowd, PhD, Research Scientist/BRFSS Epidemiologist-Coordinator, Center for Health Statistics, NJDHSS, provided county-level statistical analyses of BRFSS data.
- Mortality data were obtained from the State Cancer Profiles<sup>a</sup> of the Cancer Control PLANET Web portal.<sup>b</sup> The State Cancer Profiles web site is sponsored by <http://www.cancer.gov>/the National Cancer Institute (NCI, a component of the National Institutes of Health, NIH) and <http://www.cdc.gov>/the Centers for Disease Control and Prevention (CDC).<sup>c</sup> The Division of Cancer Prevention and Control (DCPC), of the National Center for Chronic Disease Prevention and Health Promotion, is the lead within CDC with respect to comprehensive cancer control program planning and services.
- The Cancer Information, Education and Research Program within the Division of Population Science at Fox Chase Cancer Center encompasses the Atlantic Region office of the NCI's Cancer Information Service (CIS).<sup>d</sup> The Atlantic Region office is one of the original NIH-funded CIS offices and serves New Jersey, Pennsylvania, and Delaware.<sup>e</sup> The NCI CIS provided each county with Consumer Health Profile maps that helped identify potential geographic areas of medically underserved populations based on consumer marketing profiles.

### ***Training and Monitoring***

Training and scientific guidance were provided under the direction of UMDNJ and OCCP<sup>f</sup>. A training and monitoring program<sup>g</sup> was developed specifically for the County Evaluators. A summary of the training sessions, the guidance documents developed during this process, and customized data sets to assist county-level capacity and needs assessments are described below.

<sup>a</sup> See <http://statecancerprofiles.cancer.gov>.

<sup>b</sup> "The Cancer Control PLANET Web portal is a collaborative effort aimed at providing access to data and resources that can help cancer control planners, health educators, program staff, and researchers design, implement, and evaluate evidence-based cancer control programs." Available at <http://cancercontrolplanet.cancer.gov>, accessed 12/10/04.

<sup>c</sup> The NIH and CDC are two of eight agencies that constitute the Public Health Service of the federal Department of Health and Human Services.

<sup>d</sup> See <http://cis.fccc.edu>.

<sup>e</sup> Fox Chase Cancer Center 2003 Scientific Report. [http://www.fccc.edu/docs/sci\\_report/Fleisher.pdf](http://www.fccc.edu/docs/sci_report/Fleisher.pdf), accessed 12/9/04.

<sup>f</sup> Stanley H. Weiss, MD and Peg Knight, RN, MEd directed all activities related to training of the County Evaluators.

<sup>g</sup> Developed by Dr. Weiss and Marcia P. Sass, ScD (UMDNJ School of Public Health).

1) Six Formal Training Sessions during Fiscal Year 2003

May 14, 2003: Introduction to the NJ-CCCP and NJCEED

May 19, 2003 (three sessions were held during the week of May 19, 2003): NJ National Public Health Performance Standards Training for Health Officers

June 3, 2003: Workshop on the Effective Use of the New 2000 US Census, focusing on cancer-related issues

June 9, 2003: Networking and Resource Training Day Cancer Information Service, Presentation by Workgroup Chairs, Dr. Baskies and Mr. Benson

June 25, 2003:

- Data reporting and resource information
- Presentation by Workgroup Chairs, Dr. Lederman and Ms. Thies
- Cancer Control PLANET training

2) Eleven Monthly Follow-up Meetings during Fiscal Year 2004

July 21, 2003:

- NCI's Cancer Information Service
- *Healthy New Jersey 2010*
- Presentation on Culturally Competent Health Promotion and Disease Prevention by Dr. Robert Like
- Presentation by Advocacy Ad Hoc Workgroup Chair, Marian Morrison

August 12, 2003:

- Presentation by Co-chairs, Elizabeth Burton and Fern Kulman, of the Access/Resource Subcommittee of the Overarching Issues Workgroup
- Report guidelines and discussion
- Distribution of county-level cancer statistics from the State Cancer Registry on the seven NJ-CCCP priority cancers

September 4, 2003:

- Presentation by Mark Guarino on Coordination with Government Public Health Partnerships, CHIPs, and LINCS agencies
- Presentation on Coalition Building by Roslyn Council
- Presentation by OCCP by Peg Knight
- Training on simple linear regression of rates against time (Part I) by Daniel Rosenblum

October 21, 2003:

- Feedback on report drafts submitted on October 8
- Presentations by Lung and Palliation Workgroup Chairs
- Training on simple linear regression of rates against time, using Excel (Part II) by Daniel Rosenblum
- Training on the calculation and use of prevalence estimates by Judith Klotz

December 2, 2003:

- Last minute questions and discussion about reports
- Presentation by Childhood Cancer Workgroup
- Discussion of future tasks, after final reports are due in December
- Peer-review and external review processes

January 29, 2004:

- Set up mini-groups for the review process
- Reviewed work load of County Evaluators and timetable
- Introduction to Epi Info by Daniel Rosenblum
- Training on need for and use of recalculated *Healthy New Jersey 2010* objectives by Judy Klotz and Stan Weiss

February 11, 2004:

- Discussed report details, roadblocks, suggestions for remediation of TELEform data collection obstacles
- Exchanged reports to begin review process
- Met as mini-groups to discuss review process
- Use of Epi Info to analyze cancer resource data (Part II) by Daniel Rosenblum

March 10, 2004:

- Exchanged reviewed reports and critiques
- Use of Epi Info to analyze cancer resource data (Part III) by Daniel Rosenblum
- Use of bladder cancer data by Lisa Roche
- Use of BRFSS data by Ken O'Dowd



- Presentation on how to present and analyze TELEform information by Jean Mouch (Camden County)
- Use of Epi Info to analyze cancer resource data (Part IV) by Jean Mouch and Daniel Rosenblum
- Doreleena Sammons-Posey emphasized the commitment of NJCEED to the C/NA process and applauded the achievements of the County Evaluators.
- Based on April 2004 report submissions:
  - Individual Action Plans developed for each county by UMDNJ and OCCP.
  - Informed each County Evaluator of their status privately
  - Assigned supervisory County Evaluators to counties in need of extra help
  - Implemented a revised timeline for the remainder of the fiscal year.

- Discussion of development of summary materials appropriate for the lay public
- Discussion on coalition building
- Report Section on Recommendations
- Training on TELEform data analysis using Epi Info by Dina Stonberg (Burlington County)

- American Cancer Society's Community Health Profiles & E-Tool
  - The county reports' contribution to enhancing ACS' CHPs and their call-in resource center
  - How to apply data in developing reasonable recommendations and do-able tasks
- Fiscal Year 2005 Projects - Tasks and Funding
- Analyses and GIS coding of the CRDNJ
- Executive Summaries and Recommendations
  - Drawn from the full C/NA
  - Data-based, prioritized

- Guidelines for developing the Capacity and Needs Assessment consisted of detailed guidance for each section, including presentation of data, appropriate data sources, interpretation of data, and formatting issues. These guidelines were revised throughout the reporting process to incorporate issues that arose.
- Guidelines for the Report Summary
- Guidelines for those peer-reviewing the Report Summary

As described earlier in Section 4, the need to systematically collect, update, and analyze resources available was identified. The Cancer Resource Database of New Jersey

constructed specifically for this project, to facilitate the county-level collection of statewide data. As a result, training on data collection and analysis was needed.

5) Recalculation of *Healthy New Jersey 2010* Objectives

Incidence and mortality rate reduction targets in the *Healthy New Jersey 2010* objectives related to the seven NJ-CCCP cancers were recalculated using the 2000 U.S. population standard in order to compare the targets to these 1996-2000 baseline incidence and mortality rates. These incidence and mortality rates are weighted averages of the actual rates for people at various ages, and there was a change in the weights used by national and state authorities between the publication of *Healthy New Jersey 2010* and the reporting of statistics used in the present assessments. This change can make new rates appear to be as much as twice as high as the corresponding old ones, without any actual change having occurred.<sup>h</sup> See Appendix H for a complete description of this process and the recalculated targets.

6) Calculation of Prevalence Estimates

One of the measures of the burden of a disease is its *prevalence*, that is, how many people have the disease at a given point in time. Estimates of cancer prevalence are not typically generated by the New Jersey State Cancer Registry or any other agency. However, it was agreed that evaluation of cancer burden should include an estimate of prevalence. Multiple methods exist for calculating prevalence. Based on consultation with various parties, a method for estimating prevalence at the county level was developed. See Appendix I for a complete description of the method for estimating prevalence.

7) Cancer Staging Data

The proportions of the priority cancers diagnosed at various stages (*in situ*, localized, regional, and distant) were compared with the corresponding staging proportions statewide and nationwide for various subpopulations. The New Jersey State Cancer Registry provided the county and state staging data, but national staging data needed to be otherwise computed. See Appendix K for a complete description of the method we developed to estimate national staging proportions and its application to New Jersey data.

8) Development of a Glossary and List of Abbreviations and Acronyms

A comprehensive glossary was developed, consisting of over 130 terms and phrases related to cancer, healthcare, demographic information, and statistics. A copy of the glossary will be provided with the distribution of the Report Summary.

## C/NA Review Process

During the development of the C/NA, the OCCP and UMDNJ each consulted with Battelle to assess the feasibility of a complete technical review of each of the full C/NAs. After reading several reports, Battelle noted the need for experts with a sophisticated epidemiology background to review these reports and recommended the following:

<sup>h</sup> Comparing the new statistics with the old targets is as much an error as comparing kilometers to miles would be without a conversion to a single unit of measurement.

- Detailed and extensive review and editing of only the Report Summaries
- Instilling greater consistency in the language of all reports
- Suggested the possibility of limited distribution of the full C/NAs

The OCCP and UMDNJ agreed with Battelle’s recommendations in general and initiated a peer-review process involving the County Evaluators for the C/NAs, which improved consistency among the reports.

## **Report Summaries**

Each county’s Report Summary is an overview of the report it accompanies and will exist as a stand-alone document. These will be the first “master” documents publicly released by the NJDHSS-OCCP. It is expected that these Report Summaries will become critical for directing the attention of public officials to policy issues and for referring them to relevant sections of the report that support policy proposals. The Report Summaries are intended to provide a detailed and comprehensive summary of the county’s assessment and provide information useful for a wide array of purposes. Two sample Report Summaries are available in Appendix M.

## ***Review and Editing of Report Summaries***

- Phase 1 – Initial technical review was conducted to verify and correct data use, analysis, and epidemiologic interpretation.<sup>i</sup>
  - Due to the complexity of the types of data and analyses, it was found to be necessary to write substantial portions of the reports centrally. Standardized text and references were added.
  - Following the technical review, discussion with the County Evaluator was initiated.
- Phase 2 – Review by the Evaluation Committee
  - The Evaluation Committee held several conference calls specifically to discuss the review process and achieve consensus on the general approach, as well as to discuss the individual county Report Summaries for five counties. The review of the individual county Report Summaries focused on the recommendations.
  - All issues and concerns raised during these reviews were incorporated into the subsequent review of other counties. Committee members who actively participated in the review process agreed that revisions have been highly responsive, addressing all of the concerns and recommendations raised.
  - All Committee members were strongly encouraged to provide feedback on each report posted. Committee members agreed to review the list of posted reports at least weekly.
- Phase 3: Copy editing was conducted by Battelle to achieve further consistency amongst reports.
- Phase 4: Task Force review and approval.

The County Evaluators also submitted a brief summary (2-3 pages) of highlights based on the previous C/NAs. The Office of Cancer Control and Prevention in consultation with UMDNJ plans to develop a Fact Sheet for each county.

<sup>i</sup> Technical editing was performed and managed by Dr. Weiss and staff.

## Summary of Findings Identified by Multiple Counties

- The lack of healthcare insurance was universally highlighted in all counties as the most critical factor affecting screening, early diagnosis, and treatment of racial and ethnic minorities, low-income, elderly, and linguistically isolated populations in particular.
- The fragmented healthcare system was also frequently cited as a barrier affecting timely access to services. Patient navigators could serve as one potential solution to these barriers, and although the need for patient navigators is generally well recognized, their services are not widely available throughout the state. Patient navigators are specifically trained to help patients, families, and caregivers navigate the various systems when dealing with cancer. Patient navigators are a link to information, programs, and resources, such as literature on coping with cancer, what to expect during chemotherapy and radiation, and dealing with side effects of treatment; support groups or other programs for information and support, financial assistance, medication needs, home health care, insurance questions, and transportation.<sup>j</sup>
- Cultural and linguistic barriers to access to medical and related services were identified in several counties.
- With the potential to directly impact the ability of populations described above to receive screening, the expansion of funding to support additional screening in the NJCEED program was recommended as a priority in every county.
- The majority of, if not all, counties recognized the need for community-level data to adequately assess the specific needs of diverse communities within each county. The NJDHSS has supported a significant increase in the number of the Behavioral Risk Factor Surveillance System (BRFSS) surveys beyond that funded by the CDC. These data, which are in the process of becoming available, will provide more reliable baseline county-level assessments for tracking of improvements related to NJ-CCCP activities. The data will be useful in somewhat better identifying populations of focus at the municipality and local levels, although the sample sizes and relatively wide confidence limits will restrict interpretation to identifying very large differences. Additional support for an expanded number of surveys is warranted to enable over-sampling of priority population groups (including priority geographic regions), to facilitate analysis of trends over time, and to identify populations for which resources may need to be targeted.
- BRFSS provides data on self-reported behavior of New Jersey residents. In addition, several counties identified the need for a formal assessment of attitudes and knowledge of risk factors among their county residents.
- Institutionalization of the C/NA process at a regular time interval (e.g. every five or ten years) was recommended by many counties to maintain an accurate assessment and comparison of local health resources and statistics over time.
- Upon examination of staging data, high percentages of unstaged cases have been observed. While this is unsurprising among the oldest age groups (65 years and older), county and statewide percentages above 10% make it difficult to compare staging data at

<sup>j</sup> American Cancer Society, see [http://www.cancer.org/docroot/COM/content/div\\_OH/COM\\_6\\_1x\\_Patient\\_Navigator.asp?sitearea=COM](http://www.cancer.org/docroot/COM/content/div_OH/COM_6_1x_Patient_Navigator.asp?sitearea=COM) and see [http://www.cancer.org/docroot/COM/content/div\\_Midwest/COM\\_11\\_2x\\_American\\_Cancer\\_Society\\_Navigator.asp?sitearea=COM](http://www.cancer.org/docroot/COM/content/div_Midwest/COM_11_2x_American_Cancer_Society_Navigator.asp?sitearea=COM)

the county and state levels and thus determine whether further resources to increase early-stage diagnosis are necessary. Among cases diagnosed during 1996-2000, more than ten percent of the cases were unstaged statewide for five of the six priority cancers for which screening has been demonstrated to improve survival<sup>k</sup>:

- Cervical cancer: 13.5%
- Colorectal cancer cases among males and females: 10.0% and 11.3% respectively
- Melanoma cases among males and females: 10.4% and 10.1% respectively
- Oral/oropharyngeal cancer cases among males and females: 11.4% and 14.1% respectively
- Prostate cancer: 16.4%

Further analysis by the NJSCR to ascertain the provenance of and reason for such large numbers of cancer reports lacking a stage at diagnosis is needed. This should be followed by measures to encourage better reporting of staging by those tumor registries that have been the source of the preponderance of the unstaged cases, or statewide, as appropriate.

### **Evaluation of the County Cancer C/NA**

Each County successfully completed a Cancer Capacity and Needs Assessment, which was the foundation for the Report Summary. The purpose of each county's Capacity and Needs Assessment was to identify the major cancer issues affecting the county and the county's available resources, or lack thereof, for cancer prevention, screening, and treatment, and to propose recommendations for improvement. These objectives were achieved, and evidence-based recommendations and interventions to address cancer control priorities at local and state levels were developed.

For each training session for the County Evaluators, an evaluation form was developed by UMDNJ and completed by those attending. The results were tabulated and presented at the next session. Feedback was used to improve and develop content for future sessions. Given the wide array of background among the County Evaluators, this continual evaluation process was critical to building essential skills in all counties.

Training of the County Evaluators was a major undertaking encompassing a range of skills and topics, including knowledge of epidemiologic concepts. The capacity and needs assessment process was designed in part to help facilitate the interim development of policies at both the county and state levels. As a result, these initiatives have enhanced the existing community health infrastructure within each county, and led to the development of a network of long-term community partners across the state.

<sup>k</sup> Lung cancer, although a priority cancer, is excluded since screening has not been demonstrated to prolong survival.

## Section 6 – County Cancer Coalitions

Individual county efforts were initially facilitated by a NJ-CCCP County Evaluator in each county, funded by the OCCP through the New Jersey Cancer Education and Early Detection (NJCEED) Program to the 25 NJCEED lead agencies. As part of the program requirements from the OCCP for the 6-month budget period from July 1, 2004 to December 31, 2004, each County Evaluator was mandated to participate in cancer coalition building at the community level. The County Evaluators were required to identify potential members for their respective community-based coalitions of diverse stakeholders, including the business community, community-based organizations, healthcare providers, volunteers, cancer survivors, the academic and research communities, community participants, local and state government, and other interested parties.

The overall goal of a community-based cancer coalition is to increase communication and collaboration among various stakeholders to achieve an integrated program, maximize resources, coordinate priorities for all coalition activities, and provide a supportive infrastructure for members and resources who will assist in the implementation of the evidence-based strategies and recommendations of the NJ-CCCP and the County C/NAs. Thus, one critical aspect of coalition building was identifying and recruiting members for each community-based coalition.

The Centers for Disease Control and Prevention (CDC) has emphasized that such coalitions be an essential part of State Breast and Cervical Cancer Early Detection Programs. The purpose of the NJCEED coalitions is to bring together a broad spectrum of community resources, minority-based organizations, and public support and awareness in order to reduce mortality and morbidity from breast, cervical, colorectal, and prostate cancers. The NJCEED coalitions are required to be at the community level; thus local coalitions were established in every New Jersey county.

Some county coalitions have developed from the NJCEED coalitions, building upon the existing foundation to expand into a countywide coalition. Others have a scope beyond cancer, such as chronic diseases. The NJCEED program addresses only four of the seven priority cancers in the NJ-CCCP (breast, cervical, colorectal, and prostate) and serves only a portion of the county's population, based on specific income- and insurance-related eligibility requirements. Thus, the new county cancer coalitions have a vision/mission different from and beyond that of the NJCEED coalitions.

The OCCP required submission of a County Cancer Coalition Building Report, as recommended by the Evaluation Committee. Baseline evaluations including the coalition's history, goals, activities, and obstacles were summarized in the reports submitted in June 2004. Reports summarizing updated information and new developments were submitted in December 2004 (see Appendix L for the guidance document for the June Coalition Building Report and the December Coalition Building Report, developed by OCCP and UMDNJ).<sup>a</sup> The June 2004 report from each

<sup>a</sup> The June and December Reports have been compiled and are available from the OCCP. Responsibility for following up with each county, compilation of all reports, and distribution to OCCP and the NJCEED office was handled by UMDNJ.

county was reviewed, and the County Evaluators were provided direction on how to amplify current strengths and work to overcome obstacles in the current coalition structures<sup>b</sup>. The June reports were reviewed, and a draft assessment was disseminated. Common issues discussed by most counties in the coalition reports were staff, resources, and procurement of funding to support them.

The county coalitions will work to decide how best to align the vision/mission of their respective coalitions with the County Capacity and Needs Assessment. To effectively promote the goals of the NJ-CCCP throughout the county, expansion of coalition efforts to the other three NJ-CCCP priority cancer (lung cancer, melanoma, and oral/oropharyngeal cancers), as well as to issues of palliation, nutrition and physical activity, childhood cancer, and advocacy, and broadening the focus of efforts to include other priority populations identified in the C/NA Report, are necessary.

As of December 2004, 19 of the 21 counties have countywide cancer coalitions in place. The Coalition Building Reports and Capacity and Needs Assessment Report Summaries are now to be utilized together by each county's cancer coalition, as well as by an array of related interested institutions in cancer prevention, detection and treatment efforts at the community level, to promote and accomplish NJ-CCCP priorities.

As shown in the table below, several of the priority cancers of the NJ-CCCP are not the focus of attention of the American Cancer Society or NJCEED, nor of any other comprehensive agency. (Indeed, NJCEED expanded to include colorectal and prostate cancer screening only in the last two years, after the initiation of the NJ-CCCP. Only three of these cancers are shared priorities of the NJ-CCCP, ACS, and NJCEED.) Thus, the countywide cancer coalitions are the only current vehicle through which all priority issues of the NJ-CCCP can be addressed at the local level. Consistent with the federal concepts of comprehensive cancer control, funding to support these coalitions is important to make progress on all aspects of the NJ-CCCP.

**Comparison of the Priority Areas of  
the NJ-CCCP, American Cancer Society, and NJCEED**

|                    | <b>NJ-CCCP</b> | <b>ACS</b> | <b>NJCEED</b> |
|--------------------|----------------|------------|---------------|
| Breast (female)    | ✓              | ✓          | ✓             |
| Cervical           | ✓              |            | ✓             |
| Colorectal         | ✓              | ✓          | ✓             |
| Lung               | ✓              | ✓          |               |
| Melanoma           | ✓              |            |               |
| Oral/Oropharyngeal | ✓              |            |               |
| Prostate           | ✓              | ✓          | ✓             |

New funding to enhance cancer coalition building at the county level, over and beyond existing NJCEED coalitions, will be available beginning in January 2005, through an RFA which was

<sup>b</sup> Performed by Ms. Anna Ruth Thies, MA, RN, the former project coordinator of the NJDHSS NJCEED program, and currently a consultant to the OCCP.

released through the NJDHSS-OCCP. Eligible applicants included NJCEED agencies and local health departments, although all were encouraged to collaborate and submit joint applications. To encourage such collaboration among agencies within each county, one award per county will be made. The organizational infrastructure of the OCCP has been enhanced through the awarding of the CDC Program Announcement 02060 Grant, which enabled the OCCP to hire two Public Health Representatives: (1) a site coordinator for the 21 counties and (2) a representative to assist coalitions and workgroups on preparing grants and procuring monies.

The American Cancer Society is developing city-level cancer initiatives in New Jersey, of which those in Newark, Paterson, and Trenton had kick-off breakfasts in 2004, while those in Jersey City, Camden, and New Brunswick are still in the planning stage. The ACS is enlisting widespread healthcare, community, government, and corporate support. Collaboration between these initiatives and the county-level efforts sponsored by the OCCP will be important over the coming years, with a coordination meeting planned for February 2005.

### **Behavioral Risk Factor Surveillance System (BRFSS) Data at the Municipality-Level**

The need for cancer statistics and BRFSS data within local communities and cities has been expressed by a variety of parties, including the County Evaluators. Optimal sampling strategies is one of the issues currently under discussion.<sup>c</sup> For example, it has been suggested that it would be useful to collect municipal-level BRFSS data for municipalities with populations greater than 50,000, in order to evaluate variations within single counties, especially in counties with major contrasts between large cities and extensive suburbs such as Camden and Essex. Similarly, for several cities, there are considerable contrasts within the city, which would require additional sampling in order to compare neighborhoods. For example, UMDNJ-NJMS and the Newark Department of Health formed a group<sup>d</sup> in October 2004 to explore issues related to Newark community surveys of health and related demographics.

### **Local Health Initiatives**

The systems and reports developed for the cancer initiatives were developed in the context of facilitating future utilization and incorporation in other broad public health initiatives that are in the formative stages, in particular the Community Health Improvement Plans (CHIPs).

As outlined by NJ regulation, *Chapter 52 - Public Health Practice Standards of Performance for Local Boards of Health in New Jersey*, which was made effective in February 2003, local health officers are now required to implement the “Local Instrument” of the CDC’s “Public Health Practice Standards Program” (<http://www.phppo.cdc.gov/nphpsp/index.asp>).

Local Health Departments, Government Public Health Partnerships (GPHPs), and Local Information Network and Communications System (LINCS) agencies continue in their efforts to coalesce county initiatives. LINCS Practice Standards Partnership Coordinators have been brought on board and are beginning to work with various county and local level coordinators. There remains a need to enhance the dissemination of information about the county C/NA efforts

<sup>c</sup> Dr. Kenneth O’Dowd is continuing to work closely with, and as part of, the Evaluation Committee.

<sup>d</sup> Chaired by Dr. Pauline Thomas (UMDNJ-NJMS) and includes representatives from the Evaluation Committee.



to the local health departments. This is being coordinated centrally by the NJDHSS. Communication locally has commenced in some counties.

The Community Health Improvement Plan is a formal written plan which includes the roles and responsibilities of all participants as well as a mechanism for accountability for agreed upon goals, objectives and services. The plan is developed through a series of timely and meaningful action steps that define and direct the distribution of essential public health services of community public health providers in a specific countywide or multi-countywide area according to partnerships and processes set forth in this chapter. All plans need to be approved by the Office of Local Health.

The County Cancer Capacity and Needs Assessments and the county cancer coalitions provide data, models, and infrastructure that are highly relevant to CHIPs.

The LINCS practice standards coordinators are responsible for developing CHIPs among all local health officers and also for the Practice Standards. The guidelines for the County C/NAs instructed County Evaluators to write a chapter that succinctly prioritizes for local health officials the county-related problems they have addressed in the report, so it could be easily incorporated into the “Local Instrument.” Involvement of local health officers is thus important since they are a public resource with a mandate to prevent illness and disease and to promote and protect the health of the public. It is envisioned that partnership with various stakeholders in the County Cancer Coalition will help enhance the capacity of local health officers to provide and/or enhance cancer services and education to their community members; involvement of local health departments will help to provide an infrastructure that supports and sustains local capacity to diminish the cancer burden at the local level.

## Section 7 – Recommendations and Summary

Based on the information from this Report, we note and recommend the following:

### **Advocacy and Opportunities for Collaboration**

- The close working relationship between the Task Force and the OCCP has proven highly effective. The rapid progress in implementing the NJ-CCCP and developing novel initiatives under the direction of the Task Force has been facilitated by the OCCP and related NJDHSS offices. Continued support for the OCCP, which is instrumental in prioritizing, coordinating, and providing structure for statewide activities, is critical for further progress.
- Given the proven effectiveness of current leadership of the Task Force and OCCP, the organizational structure and leadership should be maintained.
- New Jersey has rapidly become a nationwide leader in comprehensive cancer control, as exemplified, for instance, by the American Cancer Society's (ACS's) adoption of the Cancer Resource Database of New Jersey as its nationwide pilot data source on cancer resources and by statements from CDC officials who oversee state cancer control programs.<sup>a</sup> The progress documented in this Report warrants continued support to sustain and expand current comprehensive cancer control efforts overseen by the OCCP.
- There has been an improvement in cancer mortality but a rise in cancer incidence. This discrepancy suggests a need to emphasize funding for comprehensive cancer control efforts, including tobacco control. Given the high incidence of cancer and its impact on the residents of New Jersey, cancer should remain a high statewide priority and the State Government should increase state funding to combat cancer.
- The universe of stakeholders involved in NJ-CCCP activities should continue to be expanded, including identification of and finding ways to enlist any under-represented groups.
- There is a continuing need to expand the dissemination of cancer-related information to the public and to healthcare professionals. The knowledge and experience of the State Librarian and the UMDNJ librarians should be utilized through their collaboration in comprehensive cancer control efforts including advice on how to incorporate, more generally, public librarians in the state.
- The lack of healthcare insurance was universally highlighted in the county Capacity and Needs Assessment Reports as the most critical factor affecting screening, early diagnosis, and treatment of racial and ethnic minorities and low-income, elderly, and linguistically isolated populations in particular. In Delaware, recent legislation increased access for cancer care.<sup>b</sup> In the absence of new national healthcare policy, the evolving experience in Delaware should be closely examined as a model for possible changes in New Jersey.

<sup>a</sup> Comments on December 6-7, 2004 by Anne Major, Program Consultant, PSB/DCPC/CDC and Phyllis Rochester, Team Lead, PSB/DCPC/CDC.

<sup>b</sup> See Delaware Governor Minner's press release: <http://www.state.de.us/governor/news/2004/09september/091404-cancer-treatment-program-unveiled.shtml>

- As was discussed at the November 2004 Evaluation Committee meeting, there is a need for collaboration with neighboring states, specifically New York, Pennsylvania, and Delaware. The Committee requested that the National Cancer Institute's (NCI's) Cancer Information Service (CIS) Atlantic Region<sup>c</sup> explore the interest of neighboring states. In addition, the ACS Eastern Division is coordinating a meeting, planned for early 2005, in which some key parties involved in comprehensive cancer control for New York State will come to New Jersey to learn about our experiences and databases. It is envisioned that this will also be the start of collaborative planning with New York. Similar endeavors with Pennsylvania and Delaware may be worthwhile.

### **Coalitions**

- Periodic status reports of the activities of each county cancer coalition should continue to be provided and formally assessed to monitor progress and identify obstacles and best practices. Periodic meetings of coalition coordinators are valuable for sharing and disseminating this information to all counties.
- These nascent county-level coalitions need to implement the findings from the Capacity and Needs Assessments (C/NAs) and county cancer coalition status reports.
- Part of the improvement in mortality will need to come from improvements in therapy and in outreach to the underserved and minority populations in this state, whose current survival is demonstrably shorter than that of other segments of New Jersey's population. Better outreach to underserved populations for participation in clinical trials is needed.
- Beginning January 1, 2005, funding for a full-time dedicated coordinator for each county will be available from the OCCP, with equal funding set aside for each county. However, based on the incidence and estimated prevalence of the seven priority cancers during the period 1996–2000, there is a wide range in the cancer burden among the counties, ranging from a low in Salem County (average of 227 new cases per year and an estimated 1,600 persons living with a cancer diagnosis) to the median in Burlington County (average of 1,358 new cases per year and an estimated 9,800 persons living with a cancer diagnosis) to a high in Bergen County (average of 3,339 new cases per year and an estimated 25,000 persons living with a cancer diagnosis).<sup>d</sup> Since the cancer burden clearly varies substantially amongst the counties, these data suggest that differential funding may be appropriate in future years. Demonstrated successful progress should weigh positively in future funding allocations.
- To maximize the use of state resources, it may be advantageous for groups of neighboring counties to form regional coalitions. Reports exploring the utility of a regional basis for cancer control in selected regions are being developed under contract to the OCCP.

### **Data Needs and Data Sharing**

- Data and databases need to be developed and made available to the county cancer coalitions to meet their need for information at the local level. For example, the Essex County C/NA Report carefully delineates major differences between the Newark region and its more suburban neighbors; furthermore, it highlights how there is considerable

<sup>c</sup> For additional information, see <http://cis.fccc.edu>

<sup>d</sup> Appendix G contains detailed statistics on each county.

diversity even within Newark<sup>e</sup>. Such local data are essential for the effective functioning of the county cancer coalitions.

- The national Behavioral Risk Factor Surveillance System (BRFSS) provides data on self-reported health behavior of adults in each state. Such data are useful for planning and evaluating health programs. The BRFSS includes estimates of screening rates for various cancers and their risk factors. To enhance the assessment at the community/local level, the NJDHSS has supported a significant increase in the number of BRFSS surveys beyond that funded by the CDC. These data are in the process of becoming available. They will provide more reliable baseline assessments for each county, which should facilitate tracking of improvements related to NJ-CCCP activities. These data will be useful to somewhat better identify populations of focus for some municipalities and large cities, although the sample sizes and relatively wide confidence limits will restrict analysis to the identification of very large differences only. Additional support for an expanded number of surveys is warranted to enable over-sampling of priority population groups, to facilitate analysis of trends over time, and to identify populations to which resources may need to be specially directed. Attention to and further research on linguistic barriers to accurate collection of survey data are needed.<sup>f</sup>
- Updated county-level and city-level<sup>g</sup> data from the New Jersey State Cancer Registry (NJSCR), which include explicit comparisons of Hispanic and non-Hispanic data, as well as more detailed breakdowns of staging data, are needed for planning and analysis.
- Since Cancer Epidemiology Services in the NJDHSS completed geocoding of its database in 2004, mechanisms to permit sharing of these data with cancer researchers outside of the NJDHSS should now be explored so that comprehensive cancer control efforts can be optimally informed while protecting the confidentiality of individual records.

### **Analysis of Existing Data**

- The recommendations in the county-level Capacity and Needs Assessments, in conjunction with the underlying data, should continue to be reviewed by the Evaluation Committee over the next six months to further assess common priorities and localized or regional issues. Some issues may merit development of special initiatives. A few examples:
  - There are high rates of lung cancer near the city of Camden. A special task force involving the NJDHSS has already begun to assess this issue, including consideration of possible environmental factors as well as exploration of the geographic boundaries of the problem and whether other cancers are involved.
  - The disproportionately high rates of prostate cancer in Essex County appear to be primarily related to the large proportion of black males in the county's population and their particularly high risk for prostate cancer. The prostate cancer Workgroup should consider including Essex County as a focus of its activities.

<sup>e</sup> The Consumer Health Profile data for Essex County provided by the National Cancer Institute's Cancer Information Service (CIS) substantiates this diversity. See Section 5 for more information on the CIS.

<sup>f</sup> Recent preliminary analyses and focus group endeavors have identified possible misunderstandings of questionnaires among Spanish speaking respondents. There may be a need for enhanced cultural and linguistic competency in the preparation and validation of non-English versions of the BRFSS and other national questionnaires.

<sup>g</sup> On selected major cities.

- There is an unexplained, apparently high incidence of certain cancers among Hispanics in some New Jersey counties.<sup>h</sup> It has been widely suggested that Hispanics may be undercounted in the U.S. Census, in part related to the presence of undocumented aliens and transient populations. Suggestions to make statistical corrections for the undercount were rejected by the U.S. Congress. The result is that the population denominators utilized for Hispanics are very likely too low, which may serve to inflate the calculated incidence and mortality rates. The extent to which this may be a contributing factor to the observed rate differences should be further explored.
- There is a continuing need for process evaluation. Critical assessments of process and relationship building would help inform the next five-year comprehensive cancer control planning cycle (for 2008–2012).
- Task Force membership is based upon gubernatorial appointment. The Task Force should continue to self-monitor its members' attendance and participation.<sup>i</sup>
- The racial and ethnic disparities in access to care and in cancer incidence, mortality, and stage at diagnosis, documented in this report and in the 21 county Capacity and Needs Assessments, need to be further evaluated.
- The ACS national call center is an example of an extremely important resource, the use of which should be encouraged in New Jersey. Therefore, it is recommended that each county cancer coalition promulgate to its community the availability of key resources, such as the ACS's national call center (1-800-ACS-2345) and the NCI's CIS Helpline (1-800-4-CANCER).
- The need for patient navigators<sup>j</sup> is generally well recognized, but their services are not widely available throughout the state. The ACS program represents one mechanism to help fill that gap. The ACS Eastern Division is committed to expanding this resource, concomitant with increased requests for utilization. It will be valuable to assess what programs and which hospitals throughout New Jersey offer patient navigation services and whether programs and legislation already exist for funding.
- American College of Surgeons guidelines for cancer registries and the NJSCR mandate minimum standards for ascertainment of staging. Continued emphasis on monitoring is necessary, and consensus on best practice methodology is recommended. Local registries with excess proportions of unstaged cancers may need to revise procedures in their

<sup>h</sup> Counties for which the cumulative five-year (1996–2000) incidence counts exceeded 100 cases in Hispanics and for which the county's incidence rates in Hispanic men and in Hispanic women were both at least approximately 10% higher than the corresponding state rates included Bergen, Burlington, Camden, Morris, and Ocean counties. Calculations based upon data received by SH Weiss in August 2003 from the New Jersey State Cancer Registry, New Jersey Department of Health and Senior Services. Cancer incidence in New Jersey by county, 1996–2000, for the New Jersey Comprehensive Cancer Control Plan county capacity/needs assessments.

<sup>i</sup> The OCCP has been maintaining these records on behalf of the Task Force.

<sup>j</sup> Patient navigators are specifically trained to help patients, families, and caregivers navigate the various systems when dealing with cancer. Patient navigators are a link to information, programs, and resources, such as literature on coping with cancer, what to expect during chemotherapy and radiation, and dealing with side effects of treatment; support groups or other programs for information and support, financial assistance, medication needs, home health care, insurance questions, and transportation. See American Cancer Society, description available at: [http://www.cancer.org/docroot/COM/content/div\\_OH/COM\\_6\\_1x\\_Patient\\_Navigator.asp?sitearea=COM](http://www.cancer.org/docroot/COM/content/div_OH/COM_6_1x_Patient_Navigator.asp?sitearea=COM) and see [http://www.cancer.org/docroot/COM/content/div\\_Midwest/COM\\_11\\_2x\\_American\\_Cancer\\_Society\\_Navigator.asp?sitearea=COM](http://www.cancer.org/docroot/COM/content/div_Midwest/COM_11_2x_American_Cancer_Society_Navigator.asp?sitearea=COM)

institutions in order to reduce the proportions of unstaged cancers; this will enhance the utility of NJSCR data.

### **Emerging Cancer Trends and Items for Further Review and Evaluation**

- Cancers that were not priorities in the NJ-CCCP will need to be evaluated for potential incorporation in future planning efforts.
- National data suggest the need to monitor changes in breast and lung cancer histology within New Jersey, due to the changing epidemiologic patterns of occurrence and differing etiologic factors.
- Some issues in the Emerging Trends chapter of the NJ-CCCP, such as what appears to be a looming epidemic of hepatocellular carcinoma (primary liver cancer), as well as emerging issues dealt with in other chapters, such as spiral CT screening for lung cancer and new approaches to screening for other cancers, will require careful assessment as to the most appropriate courses of action.
- Other issues in the Emerging Trends chapter of the NJ-CCCP may require the formation of new issue-specific groups, or assignment to existing Workgroups or Committees, in order to explore the matters in more detail. For example, the OCCP has identified that forming a group to focus on survivorship issues would increase visibility of and facilitate progress on these important issues.
- The Task Force will need to evaluate new emerging issues described in this report, such as the recent increase in thyroid cancer incidence, as well as some long-term trends (cancers of the kidney and renal pelvis in females, cancers of the bladder, and cancers of the liver and bile duct in males).
- Guidance from the Task Force and its Evaluation Committee regarding all of the above issues will be important over the next two years of the Plan and during development of the next five-year plan. Statistical data, including appropriate data from the NJSCR, will be needed to facilitate these efforts.

### **Summary**

In a very short period of time, tremendous progress has been made. In comparison to other states, New Jersey has moved ahead quite rapidly and is poised for further advancement in its comprehensive cancer control efforts. To capitalize on this, continued commitment from all parties will be required and adequate financial resources will need to be allocated.

The progress over the last two years is attributable to the close collaboration of government and quasi-governmental agencies (e.g., the National Cancer Institute's Cancer Information Service), academia, and the nonprofit sector both nationally (e.g., the American Cancer Society) and locally. The corporate sector, which has contributed to a lesser extent so far, needs to be further engaged. Collaboration and coordination between the American Cancer Society's city initiatives and the county-level efforts sponsored by the OCCP will be important over the coming year.

Training of the County Evaluators has enhanced the infrastructure of the statewide efforts. The infrastructure developed so far will be utilized to encourage and facilitate grant applications from private sources, government, and other public sources. The stability afforded by the CDC grant to the OCCP (in the form of a cooperative agreement) is an important start in this direction.

Encouraging all organizations to apply for cancer-related grants will maximize progress in the state.

The State Librarian and UMDNJ librarians have been collaborating on a series of endeavors to expand access to reliable health information, particularly for the elderly and medically underserved. The web site [www.healthynj.org](http://www.healthynj.org), developed and maintained by the librarians, focuses on all health issues. It now has limited information specific to cancer, but its administrative infrastructure provides a foundation for future widespread dissemination of cancer-related information. All parties recognize the crucial nature of education and information dissemination as part of comprehensive cancer control. In conjunction with the other web-based efforts led by UMDNJ on behalf of the OCCP, as described in this Report, as well as nationally-based web sites, expansion of [www.healthynj.org](http://www.healthynj.org) may be an efficient mechanism and nexus for promulgating cancer-related information to the public. The OCCP and UMDNJ web sites include other newly developed and mutually linked pages relevant to this project.

Planning for the development of the next five-year plan will commence in 2005. Integral to this effort will be the careful analyses of the information collected during the first two years of implementation of the NJ-CCCP, including all of the Capacity and Needs Assessments and the databases described in detail in this Report. Continuing systematic analyses can be expected to lead to the Task Force developing additional specific and detailed recommendations, helping as well to shape the execution of the remaining three years of the current Plan.

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<sup>a</sup> These were included in the unabridged report, and are available upon request from the OCCP.



## **Appendix A**

### **Evaluation Committee and the Evaluation Team**

**This Report is submitted to the Governor's Task Force on Cancer Prevention, Early Detection and Treatment in New Jersey  
on behalf of the Evaluation Committee and the Evaluation Team  
by the Evaluation Committee Chair, Stanley H. Weiss, MD.**

**Report prepared under the auspices of the Task Force Evaluation Committee**

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## Evaluation Committee Members and Evaluation Team

### *The Evaluation Committee*

Comprised of Task Force members and key representative stakeholders who advise the Task Force and guide the Evaluation Team. The Committee members, listed in alphabetical order, are:

- Joseph Aiello, *Research Scientist, NJDHSS*
- Cynthia Ayres, PhD, RN, *Director, Health Systems & Collaborations, American Cancer Society*
- Arnold Baskies, MD, FACS, *Task Force Chair*
- Elizabeth Burton, RN, MPH, *Bergen County NJCEED Coordinator, Access & Resources Co-Chair*
- Linda Fleisher, MPH, *Director, Cancer Information, Education, and Research Program, Division of Population Science, Fox Chase Cancer Center and Atlantic Region Office of the NCI's Cancer Information Service*
- Mark Fulcomer, PhD, *former Director for the Center for Health Statistics, currently Assistant Professor, The Richard Stockton College of New Jersey, Public Health Program, and UMDNJ*
- Mark Guarino, MPH, *Assistant Division Director, Office of Public Health Preparedness, NJDHSS*
- Margaret L. Knight, RN, MEd, *Executive Director, Office of Cancer Control and Prevention, NJDHSS*
- Fern Kulman, RN, MS, CHES, *Health Educator, Woodbridge Health Department*
- Nancy Librera, MA, BSN, *Administrator, Oncology Services, The Valley Hospital*
- Elizabeth Moody, *Public Health Practice Liaison, Division of Local Public Health Practice and Regional Systems Development, NJDHSS*
- Kenneth J. O'Dowd, PhD, *Research Scientist/BRFSS Epidemiologist-Coordinator, Center for Health Statistics, NJDHSS*
- Doreleena Sammons-Posey, SM, *Director, Chronic Disease Prevention and Control Services, NJDHSS*
- Michelle Tropper, MPH, *Vice President, Strategic Health Initiatives, American Cancer Society*
- Stanley H. Weiss, MD, FACP, *Chair of the Evaluation Committee, Professor, UMDNJ-NJMS*

Former members of the Evaluation Committee:

- Betsy Kohler, MPH, CTR, *Director, Cancer Epidemiology Services, New Jersey State Cancer Registry, NJDHSS*
- Julane Miller-Armbrister, MSW, *Healthcare Consultant*

## ***The Evaluation Team***

UMDNJ Professionals who have been providing support for the initial phases of this Team and its related activities include:

- Susan Collini, MPH (through June 2004)
- Alan C. Diamond (through June 2004)
- Shelly Gelbman
- William E. Halperin, MD
- David L. Hom, MS
- Eduardo Iturrate, BS
- Jung Y. Kim, MPH
- Judith B. Klotz, MS, DrPH
- Loretta L. Morales, MPH
- Daniel M. Rosenblum, PhD
- Marcia M. Sass, ScD
- Azadeh Tasslimi, BS

Consultants:

- A. Ruth Thies, MA, RN
- Battelle Centers for Public Health Research and Evaluation:
  - Joanne P. Abed, PhD
  - Jennifer Brustrom, PhD
  - Stephanie M. Gray
  - Shyanika Wijesinha Rose, MA

Staff of NJDHSS offices have also provided support for this Team, under the leadership of:

- OCCP: under the oversight of Ms. Knight:
  - Sharon Smith, MPH
  - Mary Ann Scepansky
- NJCEED: Ms. Sammons-Posey:
  - Candido Africa, III, MD
  - Roslyn Council, MSW
- New Jersey State Cancer Registry: Ms. Kohler:
  - Lisa Roche, PhD, MPH
  - Lisa E. Paddock, MPH
- Center for Health Statistics: Kenneth J. O'Dowd, PhD

Staff of the Atlantic Region office of the National Cancer Institute's Cancer Information Service based at Fox Chase Cancer Center have provided support for this Team, under the leadership of Ms. Fleisher:

- Evelyn González, MA
- Shari Short, MA

## **Appendix B**

### **Current Task Force Members, Workgroups, and Standing Committees**

#### ***Task Force Members (as of December 2004):***

Arnold Baskies, MD (Chair), Rancocas Hospital, Our Lady of Lourdes Health System

Ansar Batool, Quality Homecare

Philip Benson, Cancer Survivor

James Chandler, MD, FACS, FCCP, UMDNJ-Robert Wood Johnson Medical School

Marco Gottardis, PhD, Bristol-Myers Squibb Company

William Hait, MD, PhD, Cancer Institute of New Jersey

Nancy Healey, Executive Director, Central and South Jersey Affiliate of the Komen Foundation

Linda Johnson, Chairperson, National Black Leadership Initiative on Cancer II, Capital Health Systems

David Lederman, DMD, Oral & Maxillofacial Pathology, New Jersey Dental Association

Nancy Librera, MA, BSN, Administrator, Oncology Services The Valley Hospital

Barbara Rabinowitz, PhD, Administrative Director, Meridian Health/ONC

George Rhoads MD, MPH, Associate Dean UMDNJ-School of Public Health

Debbie Salas-Lopez, MD, MPH, Chief, Division of Academic Medicine, Geriatrics, and Community Programs, UMDNJ-New Jersey Medical School

Michelle Tropper, MPH, Vice President, Strategic Health Initiatives, American Cancer Society, Eastern Division

Firoozeh Vali, PhD, New Jersey Hospital Association

James Robert Wong, MD, Chair, Department of Radiation Oncology, Morristown Memorial Hospital

Chung Yang, PhD, Laboratory for Cancer Research, College of Pharmacy, Rutgers, The State University of New Jersey

## ***Workgroups and Standing Committees***

| <b>Workgroup</b>                | <b>Chairperson</b>         | <b>Relevant NJ-CCCP Chapter(s) Strategies</b> |
|---------------------------------|----------------------------|---|
| Palliation                      | Joan Monaghan, MS, RN, APN | 3   |
| Nutrition and Physical Activity | Elisa V. Bandera, MD, PhD  | 4   |
| Childhood Cancer                | Beverly Ryan, MD           | 5   |
| Breast Cancer                   | Barbara Waters             | 6   |
| Cervical Cancer                 | Phillip Glass, MD, FACOG   | 7, 13*  |
| Colorectal Cancer               | Linda Johnson, CTR         | 8   |
| Lung Cancer                     | Edward Kazimir, PhD, MBA   | 9   |
| Melanoma                        | Arnold M. Baskies, MD      | 10  |
| Oral and Oropharyngeal Cancer   | David Lederman, DMD        | 11, 13*                                       |
| Prostate Cancer                 | Phillip D. Benson          | 12  |

| <b>Standing Committee</b> | <b>Chairperson</b>         | <b>Relevant NJ-CCCP Chapter(s) Strategies</b> |
|---------------------------|----------------------------|---|
| Advocacy Ad Hoc           | Marian Morrison            | 2   |
| Evaluation                | Stanley H. Weiss, MD, FACP | 1, 13*, 14, 15                                |
| Funding/Resources         | Arnold M. Baskies, MD      | 14  |

\* The following sections of Chapter 13, Emerging Trends, have not yet been specifically assigned:

- Access to Clinical Trials
- Cancer Survivorship
- Complementary and Alternative Medicine

## **Appendix C**

### **Chronology of Key Milestones**

#### **by the NJDHSS Office of Cancer Control and Prevention (OCCP)**

#### **2001 – 2002**

During 2001–2002, the OCCP provided structure, organization, and direction for statewide activities of eight Workgroups and five Subcommittees, engaging 327 volunteers and holding four Task Force meetings.

As part of the Relationship Building and Awareness Campaigns:

- Presentations were made to: NJPRO Partnership for Prevention, NJCCR Advisory Group, TRANJ, NJLINCS, Prostate Summit, and the Breast/Cervical Coalition
- The OCCP also met with representatives from: the American Cancer Society (ACS), Office of Minority Health, Center for Health Statistics, Senior Services, Office of Communications, CINJ, and ISPT
- Development of the OCCP web site was initiated.

Positioned the OCCP for additional revenue sources by:

- CDC Grant which was approved but not funded
- Ongoing relationship with CDC through quarterly nationwide conference calls and monthly technical assistance dialogues.
- Pursuing revenue sources through pharmaceutical leads

#### **November 2002 – October 2003**

Major accomplishments from November 2002 to April 2003 centered on implementation initiatives driven by the Governor’s charge to the Task Force to “continue their mission” and supported by \$3.25M from the state. From May to October 2003, major accomplishments centered on successfully moving forward the implementation of the Comprehensive Cancer Control Plan.

#### **Infrastructure**

- Health Service Grants were awarded to 25 NJCEED lead agencies for conducting the Capacity and Needs Assessment, local cancer coalition building, and implementation of the CCCP at the community level.
- Training services from UMDNJ-SPH were procured for the County Evaluators
- Initiation of the statewide Capacity and Needs Assessment by the 25 NJ-CCCP County Evaluators began in May 2003.
- The Task Force was re-convened and its three Standing Committees (Advocacy Ad Hoc, Evaluation, and Funding/Resources) were initiated during November 2002 through April 2003. Ongoing support was provided to the Task Force, its three Standing Committees, and twelve Workgroups through the remainder of 2003 and then throughout 2004.

- Evaluation services from UMDNJ-NJMS were procured.
- With the assistance of UMDNJ and Battelle CPHRE, an internal monitoring program was developed to codify the Comprehensive Cancer Control Plan, track implementation by stakeholders, and enable evaluation for biennial reports to the Governor and the next planning cycle.

- In January 2003, a successful Governor’s press conference was held to officially announce the NJ-CCCP.
- The NJ-CCCP was widely distributed to the many constituencies involved in its development and implementation.
- The OCCP web site became operational.
- The melanoma public awareness campaign was launched in collaboration with the Division of Family Health Services, NJDHSS.
- Retention of initial stakeholders and recruitment of additional constituencies which numbered over 400 by October 2004 attest to the success of the ongoing awareness campaign of the NJ-CCCP.

- Nationally: CDC, Sister States
- Locally: ACS, NJPRO, NJ Public Health Council, and CINJ

- October: The Task Force's two standing committees, Evaluation and Advocacy Ad Hoc, were inaugurated, as stipulated in the NJ-CCCP, bringing the total number of Committees to 15, with over 500 volunteers being supported by the OCCP.
- November: The Oral Cancer Workgroup led the way with the first collaborative grant submission to the NIH; it was approved but not funded.
- December: The final draft of the first ever, statewide Capacity and Needs Assessment on cancer-related activities in New Jersey was submitted to the Evaluation Team.
- January: The Colorectal Cancer Workgroup and the Nutrition/Physical Activity Workgroup merged to pilot a faith-based initiative in Mercer County, "Body and Soul," addressing nutrition, physical activity, and a colorectal cancer awareness message. This was the first collaboration among separate Workgroups.
- February: OCCP submitted a grant application for the first time to the CDC Comprehensive Cancer Control Program. The grant was awarded and funded, effective September 2004.
- March: OCCP was a major sponsor of the special television program, "Diagnosis: Cancer," broadcasted by the New Jersey Network, which featured the Commissioner, the Task Force Chair, and many Task Force members. It focused on issues such as clinical trials, disparities, survivorship, and trends in cancer research.
- April: The Childhood Cancer Workgroup commenced planning for a statewide conference on survivorship, projected for May 2005 (funding to be identified).

- May: The Prostate Cancer Workgroup supported the national “Barbershop” initiative, led by a Workgroup member. “Barbershop” is a partnership of licensed barbers trained as lay health educators by healthcare providers and targets the patrons of local barbershops with a prostate cancer screening message.
- June: 126 school districts in-serviced on this first Train-the-Trainer program reflecting school-based strategies addressed in the NJ-CCCP. This is the first joint effort accomplished in collaboration with the Department of Education, the ACS, Family Health Services, and Action for Healthy Kids.
- July: OCCP’s first RFA, “Implementing the Comprehensive Cancer Control Plan at the County Level” was developed.
- August: The Palliation Workgroup determined introducing Schwartz Rounds to healthcare providers in New Jersey would be its focus. This initiative will include hospice organizations – a first for the Schwartz Foundation, who supports this successful forum in Massachusetts.
- September: The OCCP was awarded Comprehensive Cancer Control funding from the Centers for Disease Control and Prevention.  
Data sharing with the ACS was discussed. Data will include OCCP data collection forms, compiled using the TELEform software to create the Cancer Resource Database of New Jersey. This will become resource information for the ACS website ([www.cancer.org](http://www.cancer.org)) and national toll-free call center (1-800-ACS-2345). New Jersey’s information will be utilized as a model for developing the [cancerplan.org](http://cancerplan.org) website.



**Appendix D**  
**Additional Information on the**  
**Cancer Resource Database of New Jersey (CRDNJ)**

The development effort of the CRDNJ included funding support from the OCCP, UMDNJ, and Strategic Innovations Inc. (Mr. Robert Schermer).

**Development of the Data Collection Instruments using TELEform® Software**

A key element in design of the forms was to enable persons to collect data locally in the field, where a computer might not be available, and for all data to be transmitted and maintained at a central location. The previous experience of the Clinical Research Group (CRG) at UMDNJ, which functioned as our central location, guided the selection and customization of the software system used, TELEform® V5.0 Elite from Cardiff™ Software. This is based on optical character recognition (OCR) technology and provides data entry of automated forms from remote (fax-entry) or central (scanner-entry) sites. Thus, forms might be completed by hand or typed. TELEform software creates and distributes paper-based forms and reads information from them with the best available accuracy. It is used in performing four steps in the data collection system at the CRG: 1) Creation/design of a new case report form or modification of an existing form easily readable by TELEform; 2) Interpretation of the completed form report using TELEform's multiple recognition engines; 3) Verification of the completed report form for correctness and validity; and 4) Storage of verified data onto a database structure for later data management. An archive of the actual raw forms is developed centrally as optical scanner images (TIF files).

Mr. David Hom and Ms. Loretta Morales of the CRG used TELEform® to convert and program the prototype paper forms developed by Ms. Collini and Dr. Weiss into standardized data collection forms (colloquially referred to as "TELEforms" during the course of the CRDNJ project), and created a new electronic database that could be used by the County Evaluators.

These "TELEforms" are copyrighted forms with standardized, requested data fields. Paper versions were designed to be faxed into a central location, saving time and mailing (and copying) expense, where they were incorporated into the electronic system described above, using OCR to translate the data from a paper form into an electronic database. OCR involves reading text from paper and translating the images into a form that the computer can manipulate. Advanced OCR systems can read text in a large variety of fonts, but they still can have difficulty with handwritten text. Thus, as an alternative, an electronic system of completion and transmission was developed with the assistance of Mr. Roger Bock (in Hudson County) so that the County Evaluators could fill these forms out electronically in a writeable PDF file, to complement the paper route of information transmission.

**Processing and Analysis of Data**

Once the TELEforms were completed for each institution they were sent to the CRG for processing. The CRG reviewed the forms, worked with County Evaluators to resolve problems, and created both Microsoft® Excel and Access database versions of the CRDNJ.



## Appendix F

### Summary Tables and Figures of Statewide Cancer Statistics

#### Comparative Summary, U.S. and New Jersey Cancer Incidence and Mortality<sup>a</sup>

Age-adjusted rates per 100,000 (U.S. 2000 Standard Million population)

| Gender   | Rate      | Race/<br>Ethnicity      | U.S. Rate* | NJ Rate** | NJ<br>Rank***         | Percent<br>Difference from<br>U.S. Rate |
|----------|-----------|-------------------------|------------|-----------|-----------------------|---|
| Combined | Incidence | All races               | 464.2      | 520.4     | 2 <sup>nd</sup> (41)  | +12.1%                                  |
|          |           | White                   | 462.7      | 524.9     | 2 <sup>nd</sup> (41)  | +13.4%                                  |
|          |           | Black                   | 464.0      | 518.3     | 4 <sup>th</sup> (36)  | +11.7%                                  |
|          |           | Hispanic <sup>‡</sup>   | n/a        | 401.8     | 3 <sup>rd</sup> (8)   | n/a                                     |
|          | Mortality | All races               | 195.6      | 203.0     | 18 <sup>th</sup> (50) | +3.8%                                   |
|          |           | White                   | 193.3      | 202.5     | 13 <sup>th</sup> (50) | +4.8%                                   |
|          |           | Black                   | 243.8      | 242.0     | 26 <sup>th</sup> (41) | -0.7%                                   |
|          |           | Hispanic <sup>‡</sup>   | 132.2      | 114.1     | 25 <sup>th</sup> (40) | -13.7%                                  |
| Males    | Incidence | All races               | 546.9      | 629.4     | 2 <sup>nd</sup> (41)  | +15.1%                                  |
|          |           | White                   | 537.3      | 622.4     | 2 <sup>nd</sup> (41)  | +15.8%                                  |
|          |           | Black                   | 612.6      | 712.5     | 2 <sup>nd</sup> (35)  | +16.3%                                  |
|          |           | Hispanic <sup>‡,b</sup> | n/a        | 525.8     | 1 <sup>st</sup> (8)   | n/a                                     |
|          | Mortality | All races               | 243.5      | 246.2     | 25 <sup>th</sup> (50) | +1.1%                                   |
|          |           | White                   | 238.8      | 242.5     | 23 <sup>rd</sup> (50) | +1.5%                                   |
|          |           | Black                   | 332.0      | 330.8     | 23 <sup>rd</sup> (40) | -0.4%                                   |
|          |           | Hispanic <sup>‡</sup>   | 167.8      | 140.0     | 25 <sup>th</sup> (35) | -16.6%                                  |
| Females  | Incidence | All races               | 409.4      | 448.2     | 2 <sup>nd</sup> (41)  | +9.5%                                   |
|          |           | White                   | 414.2      | 461.4     | 2 <sup>nd</sup> (41)  | +11.4%                                  |
|          |           | Black                   | 367.8      | 392.0     | 10 <sup>th</sup> (32) | +6.6%                                   |
|          |           | Hispanic <sup>‡,c</sup> | n/a        | 319.2     | 4 <sup>th</sup> (8)   | n/a                                     |
|          | Mortality | All races               | 164.1      | 176.4     | 6 <sup>th</sup> (50)  | +7.5%                                   |
|          |           | White                   | 163.2      | 178.0     | 5 <sup>th</sup> (50)  | +9.1%                                   |
|          |           | Black                   | 191.7      | 190.7     | 23 <sup>rd</sup> (39) | -0.5%                                   |
|          |           | Hispanic <sup>‡</sup>   | 108.6      | 97.4      | 18 <sup>th</sup> (33) | -10.3%                                  |

\* U.S. incidence rates are for 2000; U.S. mortality rates are for 2001.

\*\* All NJ rates are for 2001.

\*\*\* The highest rate is ranked first, which corresponds to the worst status. Following the rank is the total number of states (excluding the District of Columbia) for which rates were available. For example, New Jersey's incidence rate for both genders and all races and ethnicities combined is the second highest amongst the 41 states for which these data were available.

<sup>‡</sup> New Jersey data for Hispanics include persons of any race. U.S. mortality rates exclude a number of states.

<sup>a</sup> Source: National Cancer Institute and Centers for Disease Control and Prevention. State cancer profiles.

Comparison tables: Incidence rates; Death rates, accessed 1/20/05. (Continually updated data may be obtained from <http://statecancerprofiles.cancer.gov/>, a site associated with <http://cancercontrolplanet.cancer.gov/>.)

<sup>b</sup> New Jersey had the highest incidence rate among Hispanic males (525.8 per 100,000) of the eight states for which rates were available (the states' incidence rates ranged from 333.9 per 100,000 to 525.8 per 100,000).

<sup>c</sup> New Jersey had the 4th highest incidence rate among Hispanic females (319.2 per 100,000) of the eight states for which rates were available (the states' incidence rates ranged from 195.4 per 100,000 to 384.4 per 100,000).

## Selected<sup>a</sup> Age-Adjusted<sup>b</sup> Statewide Cancer Statistics, 1996–2000<sup>c</sup>

|  | Estimated<br>Prevalence <sup>d</sup> | Incidence per<br>100,000 <sup>e</sup> | Mortality per<br>100,000 <sup>e</sup> |
|--|--------------------------------------|---------------------------------------|---------------------------------------|
| <b>All cancers,<sup>f</sup> New Jersey</b>   |                                      |                                       |                                       |
| Male   | 126,779                              | 628.7                                 | 261.1                                 |
| Female   | 192,698                              | 453.7                                 | 181.6                                 |
| <b>Summary of the NJ-CCCP Priority Cancers</b>                                     |                                      |                                       |                                       |
| Males:<br>Prostate,<br>Colorectal, Lung, Melanoma,<br>Oral/Oropharyngeal           | 83,121                               | 401.6                                 | 145.8                                 |
| Females:<br>Breast, Cervical,<br>Colorectal, Lung, Melanoma,<br>Oral/Oropharyngeal | 121,823                              | 277.5                                 | 99.6                                  |
| <b>NJ-CCCP Priority Cancer by Gender</b>   |                                      |                                       |                                       |
| Breast, female   | 74,236                               | 138.5                                 | 31.3                                  |
| Cervical, female   | 8,377                                | 10.9                                  | 3.1                                   |
| Colorectal, male   | 15,141                               | 79.0                                  | 29.5                                  |
| Colorectal, female   | 21,483                               | 54.4                                  | 20.1                                  |
| Lung, male   | 4,734                                | 92.5                                  | 74.8                                  |
| Lung, female   | 5,962                                | 55.4                                  | 41.6                                  |
| Melanoma, male   | 7,598                                | 20.1                                  | 4.4                                   |
| Melanoma, female   | 9,094                                | 11.9                                  | 1.9                                   |
| Oral/Oropharyngeal, male   | 3,879                                | 15.7                                  | 4.2                                   |
| Oral/Oropharyngeal, female   | 2,671                                | 6.4                                   | 1.6                                   |
| Prostate, male   | 51,769                               | 194.3                                 | 32.9                                  |

<sup>a</sup> Based upon the NJ-CCCP.

<sup>b</sup> Age-adjusted to 2000 U.S. Census population standards. Age-adjustment is used to describe rates in which statistical procedures have been applied to remove the effect of differences in composition (specifically, variations in age distribution) of the various populations. This is important in order to portray an accurate picture of the burden of cancer, since cancer is known to disproportionately affect persons of differing ages.

<sup>c</sup> Sources: New Jersey State Cancer Registry for incidence; National Cancer Institute for mortality (Personal communications from M Eisner to A Tasslimi. September, 2004.). Rates are average annual rates during the time period 1996 through 2000.

<sup>d</sup> Prevalence is the measurement of burden of disease in the population at a particular point in time. Within this report, it represents the number of people alive who have ever been diagnosed with the disease. Prevalence figures given here are rough theoretical estimates, based on a number of assumptions, and computed by applying national prevalence-to-incidence ratios to each county's average annual crude incidence count for the five years 1996–2000, separately for each gender. Actual prevalence is likely to be of the same order of magnitude as the estimate. See Appendix I for methodology used to calculate prevalence.

<sup>e</sup> Incidence and mortality are gender-specific, average annual rates, not counts, age-adjusted to 2000 U.S. Census population standards. Age-adjustment is used to describe rates in which statistical procedures have been applied to remove the effect of differences in composition (specifically, variations in age distribution) of the various populations. This is important in order to portray an accurate picture of the burden of cancer, since cancer is known to disproportionately affect persons of differing ages.

<sup>f</sup> “All cancers” represents the sum of all invasive cancer during the time period, not just the seven cancers below.

## Summary Tables and Figures of Statewide Cancer Statistics, 1996–2000 (continued)

|                                 | Incidence <sup>a</sup>           |         |                         | Mortality <sup>b</sup>           |        |                         | Estimated Prevalence <sup>c</sup> |                         |
|---------------------------------|----------------------------------|---------|-------------------------|----------------------------------|--------|-------------------------|-----------------------------------|-------------------------|
|                                 | Rate per<br>100,000 <sup>d</sup> | Counts  | % of NJ-CCCP<br>Cancers | Rate per<br>100,000 <sup>d</sup> | Counts | % of NJ-CCCP<br>Cancers | Counts                            | % of NJ-CCCP<br>Cancers |
| <b>Males</b>                    |                                  |         |                         |                                  |        |                         |                                   |                         |
| NJ-CCCP Priority Cancers:       |                                  |         |                         |                                  |        |                         |                                   |                         |
| Colorectal                      | 79.0                             | 13,907  | 19%                     | 29.5                             | 4,996  | 20%                     | 15,141                            | 18%                     |
| Lung                            | 92.5                             | 16,679  | 23%                     | 74.8                             | 13,260 | 53%                     | 4,734                             | 6%                      |
| Melanoma                        | 20.1                             | 3,726   | 5%                      | 4.4                              | 780    | 3%                      | 7,598                             | 9%                      |
| Oral/ Oropharyngeal             | 15.7                             | 2,960   | 4%                      | 4.2                              | 773    | 3%                      | 3,879                             | 5%                      |
| Prostate                        | 194.3                            | 35,359  | 49%                     | 32.9                             | 5,126  | 21%                     | 51,769                            | 62%                     |
| Total, NJ-CCCP Priority Cancers | 401.6*                           | 72,631  | 100%                    | 145.8*                           | 24,935 | 100%                    | 83,121                            | 100%                    |
| All Other Cancer Sites          | 227.1*                           | 41,315  |                         | 115.3*                           | 20,149 |                         | 43,658                            |                         |
| Total, All Cancers              | 628.7                            | 113,946 |                         | 261.1                            | 45,084 |                         | 126,779                           |                         |
| <b>Females</b>                  |                                  |         |                         |                                  |        |                         |                                   |                         |
| NJ-CCCP Priority Cancers:       |                                  |         |                         |                                  |        |                         |                                   |                         |
| Colorectal                      | 54.4                             | 13,805  | 21%                     | 20.1                             | 5,241  | 21%                     | 21,483                            | 18%                     |
| Lung                            | 55.4                             | 13,592  | 20%                     | 41.6                             | 10,350 | 42%                     | 5,962                             | 5%                      |
| Melanoma                        | 11.9                             | 2,783   | 4%                      | 1.9                              | 470    | 2%                      | 9,094                             | 7%                      |
| Oral/Oropharyngeal              | 6.4                              | 1,537   | 2%                      | 1.6                              | 404    | 2%                      | 2,671                             | 2%                      |
| Breast                          | 138.5                            | 32,474  | 49%                     | 31.3                             | 7,666  | 31%                     | 74,236                            | 61%                     |
| Cervical                        | 10.9                             | 2,469   | 4%                      | 3.1                              | 715    | 3%                      | 8,377                             | 7%                      |
| Total, NJ-CCCP Priority Cancers | 277.5*                           | 66,660  | 100%                    | 99.6*                            | 24,846 | 100%                    | 121,823                           | 100%                    |
| All Other Cancer Sites          | 176.2*                           | 42,550  |                         | 82.0*                            | 20,825 |                         | 70,875                            |                         |
| Total, All Cancers              | 453.7                            | 109,210 |                         | 181.6                            | 45,671 |                         | 192,698                           |                         |

\* These rates represent the sum of the age-adjusted incidence or mortality rates of the seven NJ-CCCP priority cancers, based on the simplifying assumption that the age distribution for each gender of the New Jersey population is similar enough to the 2000 U.S. standard population.

<sup>a</sup> Source for incidence rates and counts: New Jersey State Cancer Registry.

<sup>b</sup> Source for mortality rates and counts: National Cancer Institute. Personal communications from M Eisner to A Tasslimi. September, 2004.

<sup>c</sup> See Appendix I for methodology of estimating prevalence.

<sup>d</sup> All rates (with the exception of those marked with an asterisk) are gender-specific, average annual rates, age-adjusted to 2000 U.S. population standards.

### Alphabetically by county

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## Appendix H

### Recalculation of *Healthy New Jersey 2010* Objectives

Within the comprehensive set of goals for preventing disease and improving the health of the state's residents in *Healthy New Jersey 2010*, some specific targets for reducing the burden of cancer in the state are defined. The indicators to measure progress toward these targets are incidence and mortality rates, screening rates, and the percentage of early-stage diagnosis.

Targets for reducing incidence and mortality are stated in terms of reductions in *age-adjusted* incidence and mortality rates. Age adjustment is a method for comparing disease rates in populations from different areas or in the same population over time. Age adjustment is needed because the likelihood of disease tends to vary with age and the fractions of people in different age groups tend to vary among different populations. For example, most types of cancer are more likely to occur among the elderly than the young, so these cancers would be more common in a county with a high elderly population than in a county with a younger population.

Adjusted rates are computed by applying the incidence rates of the various age groups in the given population to the age distribution of a standard population. This is done by multiplying the incidence rate of each age group by the proportion of individuals in that age group in a reference population (such as the U.S. population in 2000) and summing up over all age groups. In other words, the age-adjusted rate is computed as a weighted average of the actual rates at various ages, using a standard set of weights<sup>a</sup> (regardless of the fractions of the actual population of interest in those age groups). This procedure allows for a comparison of rates among different populations while controlling for different age distributions of those populations. (One can think of it as handicapping populations that would otherwise unfairly be at a disadvantage due to an age distribution that includes larger fractions of people in the more susceptible ages.)

A change in the standard reference population used for age adjustment (that is, the weights used in the weighted average of the rates of the various age groups) results in an automatic increase or decrease in the age-adjusted rate. That change can be quite dramatic if the new reference population's age profile differs substantially from that of the old reference population. This artificial change in age-adjusted rates is independent of the underlying actual rates in the populations being observed.

When the statistics for *Healthy New Jersey 2010* objectives were generated, it was standard national procedure to use the age proportions in the U.S. population for 1940 for mortality and for 1970 for incidence for age adjustment. Hence the *Healthy New Jersey 2010* targets for incidence and mortality were based on rates age-adjusted to the 1970 and 1940 standard populations, respectively.

More recent data, however, such as those used in the county Capacity and Needs Assessments, are now computed using the U.S. population for 2000 as their reference for age adjustment for both incidence and mortality. Therefore, the originally published *Healthy New Jersey 2010*

<sup>a</sup> These weights are usually derived from the proportions of people in the various age groups in a standard reference population.

targets cannot be used to assess current incidence and mortality rates under the new adjustment procedures. Such comparisons require the recomputation of those targets to reflect the same age adjustment, i.e., to the 2000 U.S. population proportions. Because of the aging of the U.S. population from 1970 to 2000, the standard population distribution is now weighted more towards the older age groups. Thus, some age-adjusted incidence and mortality rates rise as much as two-fold, as a result of the change to utilizing the 2000 U.S. population as a standard. This change is purely a statistical artifact, but it exemplifies why it is critical to ensure that the same standardized population has been used when comparing data from various sources.

As of 2003, the NJDHSS had not yet recalculated *Healthy New Jersey 2010* objectives using the 2000 reference population, so Dr. Weiss recommended that a recomputation to incorporate the new population standard was needed for comparison with 2000-based incidence and mortality rates being utilized for the county Capacity and Needs Assessments. The approach was discussed with and approved by the Evaluation Committee, and implemented by Dr. Judith B. Klotz with the knowledge and consent of the Cancer Epidemiology Services and the State Epidemiologist

The basic technique for recalculating the 2010 objectives using 2000 population standards was to start with the percentage change in going from the original observed rates to the original targets, and then apply that same percentage to the recomputed rates in order to derive the newly adjusted targets. Some judgment was necessary, for example when targets were given separately for different genders and races, to ensure that the relationship of percentage reduction targets remained the same when they were recomputed using the new population standard. These considerations are noted in the comments accompanying the newly computed targets. (Targets for distribution of stages at diagnosis did not need to be updated, since these proportions are independent of age-adjustment.)

Recomputation was performed only for the *Healthy New Jersey 2010* objectives pertaining to incidence and mortality rates for the seven NJ-CCCP priority cancers and for which data were available to the Capacity and Needs Assessment (C/NA) process.<sup>b</sup> Thus, too, screening behavior data were not included in the recalculations since adequate baseline data were not yet available. The table below explains precisely which *Healthy New Jersey 2010* objectives pertaining to the NJ-CCCP have been recalculated.

<sup>b</sup> For example, county-level data on incidence of “rectal and rectosigmoid cancer” (a subset of colorectal cancers) were requested from the NJSCR. However, the NJSCR only provided data on the entire priority cancer groupings for the C/NA process, so the 2010 objective on the rectal and rectosigmoid subsite was not recalculated.



**Summary of Healthy New Jersey 2010 Objectives  
Pertaining to the NJ-CCCP with respect to Recalculations**

| <b>Objective #</b> | <b>Summary of Objective Topic</b>       | <b>Addressed in Recalculation?</b> | <b>Comments / Explanations</b>   |
|--------------------|---|------------------------------------|--|
| 4C.1               | Female breast cancer mortality          | Yes                                |  |
| 4C.2               | Female breast cancer screening          | No                                 | <ul style="list-style-type: none"> <li>County-level baseline BRFS data were not available;</li> <li>Age adjustment is not relevant here.</li> </ul>  |
| 4C.3               | Female breast cancer stage of diagnosis | Yes                                | <ul style="list-style-type: none"> <li>No change because age adjustment is not relevant here.</li> </ul>   |
| 4C.4               | Cervical cancer mortality               | Yes                                |  |
| 4C.5               | Cervical cancer screening               | No                                 | <ul style="list-style-type: none"> <li>County-level baseline BRFS data were not available;</li> <li>Age adjustment is not relevant here.</li> </ul>  |
| 4C.6               | Cervical cancer incidence               | Yes                                |  |
| 4C.7               | Prostate cancer mortality               | Yes                                |  |
| 4C.8               | Colorectal cancer mortality             | Yes                                |  |
| 4C.9               | Rectal & rectosigmoid cancer incidence  | No                                 | <ul style="list-style-type: none"> <li>Separate data on the incidence of these distal colorectal cancers was not available to our project. (The data we had from NJSCR on colorectal cancer incidence was not further broken down by site.)</li> </ul> |
| 4C.10              | Colorectal cancer screening             | No                                 | <ul style="list-style-type: none"> <li>County-level baseline BRFS data were not available;</li> <li>Age adjustment is not relevant here.</li> </ul>  |
| 4C.11              | Lung cancer mortality                   | Yes                                |  |
| 4C.12              | Melanoma incidence                      | Yes                                |  |
| 4C.13              | Oral cancer stage of diagnosis          | Yes                                | <ul style="list-style-type: none"> <li>No change because age adjustment is not relevant here.</li> </ul>   |

Both published and our recalculated *Healthy New Jersey 2010* targets are shown in the table on the next two pages. As of December 2004, the NJDHSS has not provided recalculated objectives for public use. If and when they do, it is possible that they may differ somewhat from the values in the table below.

| <b>Healthy New Jersey 2010 Targets</b>                                      |                               |               |                           |                               |                           |  |               |                               |
|---|-------------------------------|---------------|---------------------------|-------------------------------|---------------------------|--|---------------|-------------------------------|
| <b>Published, based on<br/>1970 or 1940 Standard Population<sup>^</sup></b> |                               |               |                           |                               |                           | <b>Recalculated using<br/>2000 Standard Population</b> |               |                               |
| <b>All rates are per 100,000</b>  | <b>1998 Baseline<br/>Rate</b> | <b>Target</b> | <b>Percent<br/>Change</b> | <b>Preferred<br/>Endpoint</b> | <b>Percent<br/>Change</b> | <b>1998<br/>Baseline</b>                               | <b>Target</b> | <b>Preferred<br/>Endpoint</b> |
| <b>INCIDENCE RATES</b>  |                               |               |                           |                               |                           |  |               |                               |
| <b>Cervical Cancer Incidence (Objective 6, p. 138)</b>                      |                               |               |                           |                               |                           |  |               |                               |
| Total age-adjusted  | 8.6                           | 5.4           | -37.2                     | 2.0                           | -76.7                     | 10.9   | <b>6.8</b>    | <b>2.5</b>                    |
| White age-adjusted  | 8.0                           | 5.4           | -32.5                     | 2.0                           | -75.0                     | 9.9  | <b>6.7</b>    | <b>2.5</b>                    |
| Black age-adjusted  | 13.9                          | 5.4           | -61.2                     | 2.0                           | -85.6                     | 18.0   | <b>7.0</b>    | <b>2.5</b>                    |
| <b>Melanoma Incidence (Objective 12, p. 142)</b>                            |                               |               |                           |                               |                           |  |               |                               |
| Total age-adjusted  | 12.4                          | 7.0           | -43.5                     | 6.2                           | -50.0                     | 15.0   | <b>8.5</b>    | <b>7.5</b>                    |
| White age-adjusted  | 14.5                          | 8.0           | -44.8                     | 7.3                           | -49.7                     | 17.4   | <b>9.6</b>    | <b>8.8</b>                    |
| Black age-adjusted  | 0.8                           | 0.3           | -62.5                     | 0.2                           | -75.0                     | 1.0  | <b>0.4</b>    | <b>0.3</b>                    |
| White males*  | 18.7                          | -----         | -----                     | -----                         | -----                     | 22.5   | <b>12.4</b>   | <b>11.3</b>                   |
| Black males*  | 0.3                           | -----         | -----                     | -----                         | -----                     | 0.7  | <b>0.3</b>    | <b>0.2</b>                    |
| White females*  | 11.2                          | -----         | -----                     | -----                         | -----                     | 14.0   | <b>7.7</b>    | <b>7.0</b>                    |
| Black females*  | 0.2                           | -----         | -----                     | -----                         | -----                     | 1.1  | <b>0.4</b>    | <b>0.3</b>                    |

<sup>^</sup> Mortality rates derived from *Healthy New Jersey 2010* are based on the 1940 U.S. population; data from the New Jersey State Cancer Registry (NJSCR) are based on the 1970 U.S. population.

\* These are new categories derived using data from the NJSCR and were not included in the published *Healthy New Jersey 2010* objectives.

– Continued on next page –

| <b>Healthy New Jersey 2010 Targets – continued</b>          |  |               |                           |                               |                           |  |               |                               |
|---|--|---------------|---------------------------|-------------------------------|---------------------------|--|---------------|-------------------------------|
| <u>All rates are per 100,000</u>                            | <b>Published, based on<br/>1970 or 1940 Standard Population^</b> |               |                           |                               |                           | <b>Recalculated using<br/>2000 Standard Population</b> |               |                               |
|   | <b>1998 Baseline<br/>Rate</b>                                    | <b>Target</b> | <b>Percent<br/>Change</b> | <b>Preferred<br/>Endpoint</b> | <b>Percent<br/>Change</b> | <b>1998<br/>Baseline</b>                               | <b>Target</b> | <b>Preferred<br/>Endpoint</b> |
| <b>MORTALITY RATES</b>                                      |  |               |                           |                               |                           |  |               |                               |
| <b>Female Breast Cancer Mortality (Objective 1, p. 134)</b> |  |               |                           |                               |                           |  |               |                               |
| Total age-adjusted  | 24.7   | 17.0          | -31.2                     | 17.0                          | -31.2                     | 31.2   | <b>21.5</b>   | <b>21.5</b>                   |
| White age-adjusted  | 24.7   | 17.0          | -31.2                     | 17.0                          | -31.2                     | 31.5   | <b>21.7</b>   | <b>21.5</b>                   |
| Black age-adjusted  | 28.1   | 23.3          | -17.1                     | 17.0                          | -39.5                     | 34.4   | <b>28.5</b>   | <b>21.5</b>                   |
| All females 50-64   | 56.2   | 47.3          | -15.8                     | 20.0                          | -64.4                     | 56.9   | <b>47.9</b>   | <b>20.3</b>                   |
| All females 65+   | 143.7  | 120.0         | -16.5                     | 103.0                         | -28.3                     | 141.4  | <b>118.1</b>  | <b>101.4</b>                  |
| <b>Cervical Cancer Mortality (Objective 4, p. 136)</b>      |  |               |                           |                               |                           |  |               |                               |
| Total age-adjusted  | 2.0  | 1.0           | -50.0                     | 0.5                           | -75.0                     | 2.9  | <b>1.5</b>    | <b>0.7</b>                    |
| White age-adjusted  | 1.8  | 1.0           | -44.4                     | 0.5                           | -72.2                     | 2.5  | <b>1.4</b>    | <b>0.7</b>                    |
| Black age-adjusted  | 3.7  | 2.9           | -21.6                     | 0.5                           | -86.5                     | 5.8  | <b>4.5</b>    | <b>0.7</b>                    |
| All females 65+   | 7.8  | 5.0           | -35.9                     | 0.5                           | -93.6                     | 7.8  | <b>5.0</b>    | <b>0.7</b>                    |
| <b>Prostate Cancer Mortality (Objective 7, p. 138)</b>      |  |               |                           |                               |                           |  |               |                               |
| Total age-adjusted  | 13.4   | 10.0          | -25.4                     | 6.2                           | -53.7                     | 33.1   | <b>24.7</b>   | <b>15.3</b>                   |
| White age-adjusted  | 11.8   | 10.0          | -15.3                     | 5.4                           | -54.2                     | 30.3   | <b>25.7</b>   | <b>13.9</b>                   |
| Black age-adjusted  | 32.0   | 25.3          | -20.9                     | 13.6                          | -57.5                     | 71.0   | <b>56.1</b>   | <b>30.2</b>                   |
| <b>Colorectal Cancer Mortality (Objective 8, p. 139)</b>    |  |               |                           |                               |                           |  |               |                               |
| Total age-adjusted  | 12.4   | 10.0          | -19.4                     | 7.0                           | -43.5                     | 23.1   | <b>18.6</b>   | <b>13.0</b>                   |
| White age-adjusted  | 12.2   | 10.0          | -18.0                     | 7.0                           | -42.6                     | 22.9   | <b>18.8</b>   | <b>13.0</b>                   |
| Black age-adjusted  | 16.3   | 14.0          | -14.1                     | 7.0                           | -57.1                     | 27.3   | <b>23.4</b>   | <b>13.0</b>                   |
| Persons 65+   | 143.0  | 122.7         | -14.2                     | 80.0                          | -44.1                     | 145.5  | <b>124.8</b>  | <b>81.4</b>                   |
| White males*  | 20.2   | -----         | -----                     | -----                         | -----                     | 26.9   | <b>22.1</b>   | <b>13.0</b>                   |
| Black males*  | 25.1   | -----         | -----                     | -----                         | -----                     | 31.3   | <b>26.9</b>   | <b>13.0</b>                   |
| White females*  | 14.7   | -----         | -----                     | -----                         | -----                     | 20.5   | <b>16.8</b>   | <b>13.0</b>                   |
| Black females*  | 19.2   | -----         | -----                     | -----                         | -----                     | 24.8   | <b>21.3</b>   | <b>13.0</b>                   |
| <b>Lung Cancer Mortality (Objective 11, p. 141)</b>         |  |               |                           |                               |                           |  |               |                               |
| Total age-adjusted  | 35.2   | 28.5          | -19.0                     | 25.0                          | -29.0                     | 55.9   | <b>45.3</b>   | <b>39.7</b>                   |
| White age-adjusted  | 35.0   | 28.5          | -18.6                     | 25.0                          | -28.6                     | 55.7   | <b>45.4</b>   | <b>39.7</b>                   |
| Black age-adjusted  | 43.8   | 31.6          | -27.9                     | 25.0                          | -42.9                     | 67.7   | <b>48.8</b>   | <b>39.7</b>                   |
| Male age-adjusted   | 46.4   | 29.0          | -37.5                     | 25.0                          | -46.1                     | 76.6   | <b>47.9</b>   | <b>39.7</b>                   |
| Female age-adjusted   | 26.6   | 25.5          | -4.1                      | 25.0                          | -6.0                      | 42.2   | <b>40.5</b>   | <b>39.7</b>                   |
| Persons 65+   | 322.1  | 296.9         | -7.8                      | 274.7                         | -14.7                     | 319.7  | <b>294.7</b>  | <b>272.7</b>                  |
| White males*  | 60.7   | -----         | -----                     | -----                         | -----                     | 75.6   | <b>47.3</b>   | <b>39.7</b>                   |
| Black males*  | 85.4   | -----         | -----                     | -----                         | -----                     | 103.7  | <b>45.3</b>   | <b>39.7</b>                   |
| White females*  | 35.0   | -----         | -----                     | -----                         | -----                     | 42.9   | <b>41.1</b>   | <b>39.7</b>                   |
| Black females*  | 37.6   | -----         | -----                     | -----                         | -----                     | 44.6   | <b>41.8</b>   | <b>39.7</b>                   |

\* These are new categories derived using data from the NJSCR and were not included in the published *Healthy New Jersey 2010* objectives.

## **Appendix I**

### **Estimation of County Cancer Prevalence**

One of the measures of the burden of a disease is its *prevalence*, that is, how many people have the disease at a given point in time. This is distinct from *incidence*, which is how many new cases of the disease were diagnosed during a given period (usually one year). Prevalence counts at a point in time for a chronic disease are usually greater than incidence counts during that year because they include people newly diagnosed and previously diagnosed people who are still living. (Prevalence counts can, however, be less than incidence counts for diseases of short duration because of complete recovery or rapid fatality). In the case of cancer, prevalence counts typically include **all** living persons who have **ever** had cancer at the given point in time, even if some of these persons are considered cured.

Prevalence data are useful to health agencies and planning agencies for assessing the current and predicted burden of cancer on the community. In particular, they facilitate planning health services for affected individuals and their families, allocating medical and allied resources, planning and administering pertinent health care facilities, and guiding research programs. All cancer survivors are traditionally counted as prevalent cases because the sequelae of many cancer treatments and the psychosocial effects of cancer diagnoses and survival often lead to lifelong healthcare services for patients and their families. Data on cancer prevalence are not typically collected by the New Jersey State Cancer Registry or other state agencies.

“Total cancer prevalence” includes all living individuals who have been previously diagnosed with the disease. Limited duration prevalence, in contrast, refers to those diagnosed within a specified number of years, such as the previous five years, 25 years, etc

For the reasons above, evaluation of the cancer burden in a county should include some estimate of total prevalence. Therefore, we devised a method for estimating the cancer prevalence in each county. The method, described below, was developed by Drs. Judith B. Klotz, Stanley H. Weiss, and Daniel M. Rosenblum. The approach was discussed orally with Cancer Epidemiology Services management, and disseminated in writing to, discussed by, and approved by the Task Force’s Evaluation Committee (including Cancer Epidemiology Services management), and has been incorporated into the Capacity and Needs Assessment Report Summaries for each county.

**National** data on cancer incidence and cancer prevalence are available from the National Cancer Institute’s Surveillance, Epidemiology, and End Results (SEER) Program. SEER combines cancer incidence data and survival data from their registries to estimate these national prevalence rates. These data were used to compute ratios of total prevalence rates to crude incidence rates for each of the relevant cancer sites (all cancers, breast, cervical, prostate, colorectal, lung and bronchus, melanoma, oral, and bladder) separately for males and females. An estimate of county total prevalence counts was obtained by multiplying these ratios by the average annual crude incidence count in each county for the 1996–2000 time period.

The application of national prevalence-to-incidence ratios to individual counties gives only a rough approximation of cancer prevalence. In particular, the estimate may greatly overestimate

or underestimate the number of prevalent cases if (1) the county's ratio of prevalent to incident cases for the disease in question differs markedly from the SEER ratio for that disease, and/or if (2) there is a sizable net migration of people into or out of the county after being diagnosed. Furthermore, the prevalence-to-incidence ratio very likely varies with age for many cancers, and therefore if a county's and nation's age distributions differ substantially, additional error may be introduced.

Nevertheless, it is common practice to apply data pertaining to a larger unit (here, the U.S. estimated by SEER) in order to make estimates pertaining to a smaller unit (here, a county) provided that the limitations and imprecision of the estimates are clearly stated.

### **PREVALENCE-TO-INCIDENCE RATIOS FOR Capacity and Needs Assessment Reports**

| <b>Cancer, Gender</b>             | <b>U.S.<br/>incidence<br/>rate</b> | <b>U.S.<br/>prevalence<br/>number</b> | <b>U.S. 2000<br/>population</b> | <b>Prevalence<br/>proportion in<br/>population</b> | <b>Prevalence rate<br/>per 100,000</b> | <b>Ratio of<br/>Prevalence<br/>to Incidence</b> |
|-----------------------------------|------------------------------------|---------------------------------------|---------------------------------|--|--|---|
|                                   | per 100,000                        |                                       |                                 | (number/<br>population)                            | (preceding column x<br>100,000)        | (preceding column/<br>incidence rate)           |
| Combined cancer, male             | 552.3                              | 4,241,699                             | 138,053,563                     | 0.0307   | 3072.5                                 | <b>5.6</b>                                      |
| Combined cancer, female           | 420.1                              | 5,313,613                             | 143,368,343                     | 0.0371   | 3706.3                                 | <b>8.8</b>                                      |
| Breast cancer, female             | 134.1                              | 2,197,504                             | 143,368,343                     | 0.0153   | 1532.8                                 | <b>11.4</b>                                     |
| Cervical cancer, female           | 9.5                                | 231,064                               | 143,368,343                     | 0.0016   | 161.2                                  | <b>17.0</b>                                     |
| Prostate cancer, male             | 162.0                              | 1,637,208                             | 138,053,563                     | 0.0119   | 1185.9                                 | <b>7.3</b>                                      |
| Colorectal cancer, male           | 66.4                               | 499,018                               | 138,053,563                     | 0.0036   | 361.5                                  | <b>5.4</b>                                      |
| Colorectal cancer, female         | 48.5                               | 541,041                               | 143,368,343                     | 0.0038   | 377.4                                  | <b>7.8</b>                                      |
| Lung cancer, male                 | 89.1                               | 174,547                               | 138,053,563                     | 0.0013   | 126.4                                  | <b>1.4</b>                                      |
| Lung cancer, female               | 53.4                               | 167,910                               | 143,368,343                     | 0.0012   | 117.1                                  | <b>2.2</b>                                      |
| Melanoma, male                    | 19.0                               | 267,432                               | 138,053,563                     | 0.0019   | 193.7                                  | <b>10.2</b>                                     |
| Melanoma, female                  | 12.1                               | 283,428                               | 143,368,343                     | 0.0020   | 197.7                                  | <b>16.3</b>                                     |
| Oral/Oropharyngeal cancer, male   | 15.8                               | 142,935                               | 138,053,563                     | 0.0010   | 103.5                                  | <b>6.6</b>                                      |
| Oral/Oropharyngeal cancer, female | 6.3                                | 78,473                                | 143,368,343                     | 0.0005   | 54.7                                   | <b>8.7</b>                                      |
| Bladder cancer, male              | 38.3                               | 353,533                               | 138,053,563                     | 0.0026   | 256.1                                  | <b>6.7</b>                                      |
| Bladder cancer, female            | 10.0                               | 125,603                               | 143,368,343                     | 0.0009   | 87.6                                   | <b>8.8</b>                                      |

*Based upon 1) incidence data from Cancer PLANET, based on SEER/NPCR 1999; 2) prevalence data from SEER based on estimates for year 2000; and 3) U.S. population from 2000 Census.*

## Appendix K

### Staging of Cancer

Staging is the process of describing the extent of spread of the disease from the site of origin at the time of diagnosis.<sup>a</sup> The stage of a cancer at its diagnosis is important to treatment and to prognosis.<sup>b</sup> For some cancers that can be detected at early stages, a late stage at diagnosis may be an indication of a failed opportunity for prevention. Therefore, the distributions of stage at diagnosis among geographic areas can help identify needs for screening and other preventive measures as well as for treatment and psychosocial support of individuals and families.

The major staging classification scheme utilized by cancer registries has four categories:<sup>a</sup>

- *in situ* (cancer is restricted to the layer of cells in which it originated, *i.e.* the disease is not “invasive”);
- localized (restricted to the organ of origin);
- regional (invasive of organs immediately surrounding the organ of origin and/or nearby lymph nodes); and
- distant (metastasized, frequently via the bloodstream, to organs which are not contiguous with the organ of origin).

Stage is determined just once for registry data – at the original time of diagnosis. Staging is determined by a combination of physical examination, laboratory tests, imaging, pathology reports, and surgical reports. For most cancers, the non-invasive tumors (the *in situ* diagnoses) are excluded from the cancer incidence rate calculations.

For many cancers, additional staging classifications exist that assist clinicians in assessing the most appropriate therapies, and these are generally tumor-specific. For example, the American Joint Committee on Cancer uses a staging classification, the TNM system, “based on the premise that cancers of similar histology or site of origin share similar patterns of growth and extension.”<sup>c</sup> This system classifies three significant events of a cancer: tumor growth (T), spread to primary lymph nodes (N), and metastasis (M).<sup>c</sup> The Union Internationale Contre le Cancer uses an identical classification scheme. Other characteristics of cancer are incorporated into other specialized staging systems. The SEER program collects data to establish an Extent of Disease at Diagnosis (EOD). Beginning in 2000, data are collected in the collaborative stage (CS) system.

An “unstaged” cancer is one for which insufficient information has been provided to classify it as one of the four major stage groups above. Due to clinical practice, the proportion of unstaged cancers varies by primary site. For some cancers, the proportion of unstaged tumors has declined over time, but for others it has remained approximately stable. No conclusion about the severity of an unstaged cancer can be made. When the proportion of unstaged cancer varies among populations, or the unstaged cancers constitute a high proportion of the cases, comparisons must be made with caution.

<sup>a</sup> American Cancer Society. Cancer Facts & Figures 2004, p. 2. Available at [http://www.cancer.org/downloads/STT/CAFF\\_finalPWSecured.pdf](http://www.cancer.org/downloads/STT/CAFF_finalPWSecured.pdf)

<sup>b</sup> National Cancer Institute. Cancer Facts. Staging: Questions and Answers. 2004. Available at [http://cis.nci.nih.gov/fact/5\\_32.htm](http://cis.nci.nih.gov/fact/5_32.htm)

<sup>c</sup> American Joint Committee on Cancer. Manual for Staging of Cancer. Beahrs OH, Henson DE, Hutter RVP, Kennedy BJ, editors. 4<sup>th</sup> ed. Philadelphia: J. B. Lippincott Company; 1992. p. 3.

The stage at which a cancer is diagnosed is often associated with overall prognosis. This is often because cancers diagnosed at earlier stages can be more effectively treated. (Note that this is not always the case, and that not all of the benefits of early diagnosis are necessarily due to better treatment. For untreated or ineffectively treated fatal diseases that are diagnosed earlier in the course of their natural history, survival after diagnosis will also be longer simply because the disease became known sooner. Thus, when screening approaches change, the distribution of diagnoses by stage will often change.)

The five-year relative survival rate, that is, the probability of surviving for five years after being diagnosed if one does not die of some other cause, is often used to summarize prognosis after a diagnosis of cancer. While five-year relative survival rates are useful in monitoring progress in the early detection and treatment of cancer, they do not represent the proportion of people who are cured permanently, since cancer can affect survival beyond five years after diagnosis. The following chart from the American Cancer Society (ACS) illustrates the differences in survival at various stages of diagnosis for the seven cancers of focus in the NJ-CCCP.<sup>d</sup> Note that in this chart, the “all stages combined” column includes the overall proportion of cases that fall into each of the subcategories as well as the unstaged, which are not shown. Also, the ACS does not publish these rates separately by gender (except for breast, prostate, and cervical).

**Percent Five-Year Relative Survival Rates by Stage of Diagnosis: 1992–1999<sup>d</sup>**

| Cancer Site         | All Stages Combined % | Local % | Regional % | Distant % |
|---------------------|-----------------------|---------|------------|-----------|
| Breast (female)     | 86.6                  | 97.0    | 78.7       | 23.3      |
| Cervical            | 71.3                  | 92.2    | 50.9       | 16.5      |
| Colorectal*         | 62.3                  | 90.1    | 65.5       | 9.2       |
| Lung*               | 14.9                  | 48.7    | 16.0       | 2.1       |
| Melanoma*           | 89.6                  | 96.7    | 60.1       | 13.8      |
| Oral/Oropharyngeal* | 57.2                  | 82.1    | 47.9       | 26.1      |
| Prostate†           | 97.5 <sup>e</sup>     | 100.0   |            | 34.0      |

\* These rates, as published by the ACS, are for males and females combined.

† The ACS and the Surveillance, Epidemiology, and End Results (SEER) Program of the NCI combine local and regional stages for prostate cancer.

**Survival.** Five-year relative survival rates are presented in this report for cancer patients diagnosed between 1992 and 1999, followed through 2000. Relative survival rates are used to adjust for normal life expectancy (and events such as death from heart disease, accidents, and diseases of old age). These rates are calculated by dividing observed 5-year survival rates for cancer patients by 5-year survival rates expected for people in the general population who are similar to the patient group with respect to age, sex, race, and calendar year of observation.

<sup>d</sup> American Cancer Society. Cancer Facts & Figures 2004, pp. 17, 54. Available at [http://www.cancer.org/downloads/STT/CAFF\\_finalPWSecured.pdf](http://www.cancer.org/downloads/STT/CAFF_finalPWSecured.pdf). The ACS table listing “oral cavity” includes oral cavity and pharynx (see page 15 of the ACS report). All survival statistics presented in this ACS publication were originally published by the SEER Program, 1973-2000, Division of Cancer Control and Population Sciences, National Cancer Institute, Bethesda, MD, in its *Cancer Statistics Review*, 2003.

<sup>e</sup> “According to the most recent data, relative 10-year survival is 84%, and 15-year survival is 56%.” (American Cancer Society, *Cancer Facts & Figures 2004*, p. 17.)

## Appendix N The Electronic Version of the NJ-CCCP

### Details on the Development of the Electronic Version of the NJ-CCCP

After an extensive review of potential options by Dr. Weiss's group, the Battelle Centers for Public Health Research and Evaluation (CPHRE), and the Office of Cancer Control and Prevention (OCCP), it was agreed to develop the electronic database utilizing Microsoft Access 2000™. MS Access was chosen for several reasons, including: 1) the availability of a "replicate" feature (described below); 2) widespread availability and maintenance of the software by a major corporation (Microsoft); and 3) administrative and security features, enabling maintenance of integrity by centralized administrators while permitting distributed access for input of new data.

Battelle CPHRE prepared a documentation manual for this electronic edition of the NJ-CCCP. For further information, please refer to the manual dated September 12, 2003 prepared by Shyanika Rose, MA, Joanne Abed, PhD, Stephanie Gray, BS, and Diana Gray, MPH of the Battelle CPHRE, under the auspices of Dr. Weiss *et al*, at UMDNJ, for the OCCP.

#### Functions of the NJ-CCCP Database (the Database)

The electronic version of the NJ-CCCP serves three main purposes (the full manual describes these in detail):

- To serve as an electronic copy of the NJ-CCCP. It contains the text and the labels (e.g., BR-2) for all NJ-CCCP chapters, goals, objectives, and strategies. It also encompasses the timelines and principal change agents, all linked together.
- To allow for the sorting and grouping of NJ-CCCP elements through the assignment of **codes**. Codes assigned to each strategy help to link the strategies by topic across chapters, and hence provide the indexing that was missing from the original NJ-CCCP. Categories of codes include: cancer site or type, continuum of care, strategy area, population factors, screening/diagnostic tests, risk factors, gender, age groups, race/ethnicity, and partners/targets for strategy. It should be noted that only the **goals**, **objectives** and **strategies** were coded, not the entire text of the NJ-CCCP.

Initial codes were developed jointly by UMDNJ, Battelle, and OCCP. These were then shared by UMDNJ (Dr. Weiss and Ms. Collini) with each of the Workgroups, eliciting their input into coding matters including ascertainment of key issues they wanted to be able to capture and reference. Only the **goals**, **objectives** and **strategies** were coded, not the entire text of the NJ-CCCP. However, the text served in some instances to assist the nosologist at Battelle in assigning relevant codes.

- To track progress in achieving strategies laid out in the NJ-CCCP. Elements that can be tracked for each strategy in the NJ-CCCP include responsible Workgroup, principal



change agents, target years for completion, tasks undertaken toward achieving the strategy, and funding leveraged to support implementation.

Utilization of each of these functions is described in detail in the full manual.

Two versions of the Database were developed. These differ in the latitude given to database administrators in terms of data entry:

1. The master version of the database allows the Central Database Administrators full access to all sections of the database for data entry and editing.
2. Partial replicates of the master database are given to Workgroup Administrators for tracking and monitoring purposes of that Workgroup, and include only the goals, objectives and strategies of the chapter for which that Workgroup is responsible. Workgroup Administrators have full access to the *Strategy Tracking Form* in their replicate, which enables them to update information on principal change agents, funding, and specific tasks undertaken. However, they are not allowed to make changes in the content of the NJ-CCCP, which has already been approved in its current form by the Task Force and the Governor, nor to the coding of the NJ-CCCP which must be done at a central level to ensure consistency. For instance, they cannot add entirely new principal change agents (although they can change which principal change agents implement a particular strategy), and they cannot change the target years for a strategy.

The development of chapter- and Workgroup-specific replicates enables each Workgroup to individually work on updates to the portion of the NJ-CCCP with which they have been invested with responsibility, at their own pace and schedule. The replicates are then sent to one of the Central Database Administrators to be merged into the Master Database. The Central Database Administrator is also able to add additional “Principal Change Agent(s)” (PCAs) to the database, so that their work and contributions can be acknowledged and tracked.

Under the direction of Dr. Rosenblum, software has been written both by the Battelle Centers and Dr. Weiss’s team at UMDNJ for the analysis of data contained in the NJ-CCCP Database. This software includes a substantial number of reporting functions.

- A hierarchical outline of all the goals, objectives and strategies in a chapter or in the whole plan (an excerpt from which is shown above as the example of the NJ-CCCP hierarchy for goal AC-1);
- An “index” into the plan (or into a single chapter) that lists strategies associated with each of the codes, and a reverse index that lists all the codes associated with each strategy;
- For each principal change agent, a list of the strategies for which that agent is responsible, available either plan-wide or separately for each chapter; and
- A detailed report on the progress of each strategy in the plan or for a single chapter, including each strategy’s target years, tasks, task descriptions and comments, and summary classifications of the status of each task and of the strategy overall.

During conversion of the NJ-CCCP to the electronic version, some gaps were identified. For example, a standardized process and mechanism to capture a change in the principal change agent or final target year have not yet been developed.

## Detailed Status Report of All NJ-CCCP Strategies

As of December 1, 2004

A detailed 493-page report of the status of all NJ-CCCP strategies as of December 1, 2004 is available upon request from the OCCP as part of the unabridged version of this report. Please refer to the main report, Section 3 “Status of the NJ-CCCP,” for a complete description of this database.

The database is being continually updated. Please contact OCCP for information on the latest version.